Experiences of Receiving a Peer Support Intervention for Family Members of Individuals with Mental Illness

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Declaration

I declare that this thesis is entirely my own work, other than the counsel of my supervisors, is an accurate reflection of work, and has not been submitted as part of another degree at the University of Limerick or any other academic institution.

Deirdre Reynolds Date: 17/4/2018

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Abstract

Background: Since the deinstitutionalisation movement, many families have taken on the responsibility of caring for their family members with severe mental illness (SMI). Despite being recognised as a fundamental resource, family members frequently report that the support they are receiving from Mental Health Services is inadequate. Peer support has become an integral component of the mental health care system, which is evolving towards a recovery-oriented system. However, the existing literature on peer support for family caregivers, of individuals with SMI, is still very limited.

Aim: To explore the lived experiences of receiving a Family Recovery Peer Support (FFRPS) pilot intervention for family caregivers of individuals with SMI.

Method: The experiences of receiving FRIENDS Family Recovery Peer Support (FFRPS), 6-session pilot intervention, were explored through

Twelve in-depth, semi-structured interviews were conducted with family caregivers who received FFRPS

Findings: Using Interpretative Phenomenological Analysis, two superordinate themes were identified: 1) "You feel all their pain" and 2) "A vital experience of growth and healing through relationship". Findings revealed that having a family member suffer with SMI was a traumatic experience, and one which caused strain within family relationships. Findings shed light on family caregivers' unmet needs for emotional support. All 12 caregivers reported that receiving FFRPS was beneficial. The significance of genuine understanding in the context of experiential similarity was repeatedly identified as invaluable. Analyses also revealed a sequential journey of recovery, and post-traumatic growth, across family caregivers' narratives. After receiving care within the FFRPS relationship, and having processed their own trauma, caregivers grew in strength and became more objective. This led caregivers to replace old strategies of providing care with mutually empowering ways of genuinely supporting their SMI family member.

Conclusion: Findings support the roll out of FFRPS as a beneficial intervention for family caregivers of individuals with SMI. The strengths and limitations of this study are considered, followed by a discussion of the potential implications for clinical practice, education and policy. Suggestions for future research are also offered.

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CHAPTER 1: INTRODUCTION

1.1 Overview of present study

One of the current challenges for service delivery in the area of mental health is the support of family members who support individuals with mental health difficulties. With the deinstitutionalisation movement, and the reduction in the number of psychiatric beds, considerable demands have been placed on many families (e.g. Fakhoury & Priebe, 2002; Kohn-Wood & Wilson, 2005). The family has been recognised as a fundamental resource for mental health service provision (Bradley, 2015). However, family members report that the support they are receiving from Mental Health Services is inadequate. For example, families have repeatedly indicated that they need, but do not get, information about their relative's illness and treatment, assistance with managing illness symptoms and support for their own anxieties and depressed moods (Hummelinck & Pollock 2006; Rose et al., 2004).

Caring for individuals with severe mental illness in the community carries a heavy burden for family members (e.g. McCann, Bamberg, & McCann, 2015; Saunders, 2003). Caregiving has been demonstrated to impact negatively on mental and physical health, subjective wellbeing, levels of self-efficacy and quality of relationships (e.g. Zauszniewski & Bekhet, 2014). Interventions that focus on family context and relationships have demonstrated potential to benefit all family members (Fadden & Heelis, 2011; Fallon, 2003).

Over the past number of decades, peer support services have grown to become an integral component of the mental health care system, which is evolving towards a recovery-oriented system (Kaplan, 2008; Sheedy & Whitter, 2009). Peer support in the mental health field can largely be seen as a process of giving and receiving support, founded on the key principles of respect, shared responsibility, and mutuality (Mead, 2003; Solomon, 2004). It is rooted in the idea that people who share similar experiences can offer help, empathy, validation, information and hope (Mead & Macneil, 2006). Increasingly, the extension of peer support for family members is being advocated for (e.g. Dixon et al., 2011; Leggatt & Woodhead, 2016). However, to date, the existing literature on peer support for family caregivers, of individuals with SMI, is still very limited.

The current study was undertaken in order to address the shortfall in research on peer support for family members of individuals with SMI. Its aims are to explore, and provide informative insights, into family members' (of individuals with mental illness) lived experiences of receiving FRIENDS Family Recovery Peer Support (FFRPS) intervention. The FRIENDS Project was born out of the Mid West ARI Project, which attempted to meet the unique need for further support, and inclusion, of family members within the Mid-West Mental Health Services. The FRIENDS project was run by a partnership between SHINE, the HSE Midwest Mental Health Service, and the Peer Support Centre — Aras Follain.

1.2 Thesis structure

The thesis is structured in the following order. Chapter 2 presents a review of relevant literature. The study's methodology is detailed in Chapter 3. Chapter 4 presents the study's findings. Lastly, Chapter 5 discusses the findings in the context of the relevant literature and clinical, educational and policy implications are identified. An outline of each chapter is provided below.

1.2.1 Chapter 2: Literature review

This chapter reviews the literature which relates to the present study. The two theoretical frameworks that underpin this study, namely Family Systems Theory (Bowen, 1978) and the Person-Centred approach (Rogers, 1951) are reviewed. The increased demand that mental illness places on families is explored. The stigmatisation of mental illness is reviewed, followed by a discussion on resilience in caregivers. Next, peer support is defined and its history traced. The empirical evidence on peer support for family caregivers is reviewed. The concept of Family Recovery is then introduced, followed by a review of recent Irish policies that were formulated based on the need for peer support. The chapter closes by outlining the rationale behind the present study and stating its research aim.

1.2.2 Chapter 3: Methodology

This chapter begins by providing the rationale behind adopting a qualitative approach to this study. Next, Interpretative Phenomenological Analysis, and the rationale underpinning its use, is discussed. 'Patient and Public Involvement', and how it was incorporated in this study is summarised. A description of the sampling procedures employed by the study is provided. Next, the specifics of the FFRPS Intervention, including the recruitment, training and supervision of FFRPS Providers are outlined. A comprehensive description of the procedures utilised during

data collection and analysis are provided. The chapter closes with a commentary on the management of ethical concerns, trustworthiness and credibility considerations, and researcher reflexivity.

1.2.3 Chapter 4: Findings

This chapter reports upon the identified, superordinate and subordinate themes from the IPA analysis. Two overarching superordinate themes, which represent caregivers' key experiences were identified. The first superordinate theme: —"You feel all their pain" — relates to how caregivers were impacted by having their family member suffer from SMI. The second superordinate theme: — "A vital experience of growth and healing through relationship" — concerns caregivers' experiences of engaging in the FFRPS 6-session intervention.

1.2.4 Chapter 5: Discussion

The final chapter provides a detailed discussion of the study's primary findings with reference to the extant literature, highlighting the additional contributions of the current study. The strengths and limitations of the study are considered, followed by a discussion of the potential implications of this research in terms of clinical practice, education and policy. Suggestions for future research are offered. This chapter closes with a critical reflection from the researcher's perspective.

CHAPTER 2: LITERATURE REVIEW

2.1 Chapter Introduction

This chapter reviews the literature which relates to the present study. The chapter begins by outlining the main search strategy that was used. Next, the two theoretical frameworks that underpin this study, namely Family Systems Theory (Bowen, 1978) and the Person-Centred approach (Rogers, 1951) are reviewed. Severe Mental Illness (SMI) is then defined and its impact on the family is examined. The increased demands that SMI places on family members is explored and the burden it creates for family caregivers is assessed. The stigmatisation of SMI is reviewed, followed by a discussion on resilience in caregivers, and in families. Next, literature on self-care and post-traumatic growth is reviewed. Peer support is defined and its history traced. Peer support for family caregivers is reviewed and the findings from studies on peer support for family members of individuals with SMI are discussed. The concept of Family Recovery is then introduced, followed by a review of recent Irish policies that were formulated based on the need for peer support. The chapter closes by outlining the rationale behind the present study and stating its research aims.

2.2 Literature Search Strategy

Peer-reviewed published articles relevant to the research topic were identified through a comprehensive search of the following databases: PsychINFO, Web of Science, PubMed, and CINAHL Plus with First Text. Due to the very limited research on peer support for family members of individuals with SMI, it was decided that a systematic review would not be suitable, and that a narrative review would be more meaningful and appropriate. A search was conducted for articles containing the terms ‘family peer support’ and ‘mental illness’ within their abstracts. The search was limited to materials published in English. 16 studies were yielded. The abstracts of these studies were reviewed and those not relevant were filtered out. In order to develop the narrative review, this procedure continued by using various combinations, and iterations, of other search terms which included: ‘family member/carer/caregiver’, ‘informal carer/caregiver’, ‘(severe) mental illness’, ‘family recovery’, ‘recovery’, ‘stigma’, ‘post-traumatic growth’ and ‘resilience’. Yielded abstracts were then reviewed and those not relevant were filtered out. Relevant articles were saved for full reading and critiquing. The reference lists, belonging to relevant articles, were then

reviewed, which led to the identification of further useful articles for review. The grey literature was also reviewed using Google Scholar.

2.3 Theoretical Framework 1: Family Systems Theory

A family is a system with boundaries, and consists of interconnected and interdependent individuals. Family Systems Theory (Bateson, 1972, cited in Carr, 2006) posits that an individual cannot be understood in isolation, but rather that the family system of the individual must be understood. To facilitate adaptation and survival, the boundary around the family must be semi-permeable, allowing the family to survive as a coherent system, yet also allowing the intake of information required for survival. According to this theory, all members of a family have roles and rules to obey within the family system. All family members are connected to each other and all members of a family influence and affect one another One person's wellbeing is related to other family members' wellbeing (Nichols & Schwartz, 2001). A change in one person's behaviour results in a change in all family members' behaviour, as each member adapts to the change (Sexton & Lebow, 2015).

When family members experience stress, anxiety generates dysfunctional patterns within the emotional systems, which influences them to react automatically, as opposed to choosing their response. This is referred to as a low level of differentiation within the system (Sexton & Lebow, 2015). The process of becoming more differentiated from one's family of origin is a central concept in Bowen's (1978) Family Systems Theory. A differentiated person is capable of acting separately from the influence of others, while avoiding polarisation (Friedman, 1991).

Differentiated people are non-reactive and are strong and clear about their personal perspectives and values. Highly differentiated individuals are flexible and capable of remaining calm during interpersonal conflicts. In contrast, poorly differentiated individuals tend to become overwhelmed by emotions and stress. Fusion with others is defined as an excessive emotional involvement in significant relationships. Emotional reactivity and fusion, often have disastrous consequences. Fused individuals react to relationship anxieties by attempting to fulfill the needs of the other, at the expense of their own needs and desires (Bowen, 1978; Skowron & Schmitt, 2003).

Having a high level of differentiation leads to more effective decision-making that has positive results for individuals and families. Studies have confirmed that differentiated individuals enjoy good physical and psychological health (Choi & Murdock 2016; Jankowsky,

Sandage, & Hill, 2013; Murdock & Gore, 2004), are less anxious (Peleg, 2005; Skowron & Dendy, 2004), are more satisfied with their lives (Vignoles, Regalia, Manzi, Golledge, & Scabini, 2006), and have high levels of satisfaction in their interpersonal relationships (Klever, 2005; Lampis, 2016; Skowron & Dendy, 2004).

2.4 Theoretical Framework 2: The Person-Centred Approach

Person-Centred therapy was developed by Carl Rogers in the 1940s. The Person-Centred approach is non-directive and trusts in the client's self-actualising tendency and believes in the client's ability to make the right choices for himself/herself (Milne, 2010). Rogers (1951) identified certain core conditions, which he believed are necessary if clients are to make progress in counselling. These core conditions describe required counsellor qualities and attitudes, which if experienced by the counsellor, and are accurately communicated to the client, will facilitate change and growth within the client (Hough, 2004). Rogers postulated that if therapists communicated the attitudes of congruence (being authentic), unconditional positive regard (deep acceptance) and accurate empathetic understanding, "clients will have the necessary freedom to explore areas of their lives that were either denied or distorted and they can become self-directing in profoundly wise ways" (Rogers, 1951).

A counsellor possessing these core conditions indicates, to the client, his/her preparedness to offer attention and a level of caring which endows the client with value and reduces the client's isolation (Thorne, 1996). Within the Person-Centred approach, it is the individual client, supported by this open and accepting relationship, who is empowered to take control over his or her own healing. The counsellor is only a useful companion in the process (Mcleod, 2003).

To be fully present and fully human with another person has been viewed as healing in and of itself (Shepherd, Brown & Greaves, 1972). Various studies have revealed that the relationship between client and therapist is an important predictor of outcome (Horvath, Del Re, Fluckiger, & Symonds, 2011; Norcross & Wampold 2011; Zilcha-Mano, McCarthy, Dinger, & Barber, 2014). Findings suggest that alliance is an active ingredient in therapy, meaning it is therapeutic in and of itself (e.g., Del Re, Flückiger, Horvath, Symonds, & 2012). Mearns and Cooper (2005) describe how the counsellor, and client in crisis, meet at relational depth very early in the counselling process. Mearns and Cooper (2005) cite this quality of connection as providing the necessary psychological holding for clients in extreme states of dissonance, which crisis creates. Findings from a recent qualitative study suggest that, working

from a Person-Centred approach, may lead to the possibility of post-crisis growth (Carrick, 2014).

2.5 Severe Mental Illness (SMI)

Severe Mental Illness (SMI) is a term used to describe severe and persistent psychiatric disability, including depression, bipolar disorder, schizophrenia and schizoaffective mood disorder, that generally has a profound impact on a persons' behaviour, cognition, affect and social functioning (American Psychiatric Association, 2000; Noordsy et al., 2002). Thus far, there is no universally agreed upon definition of SMI. Ryan and Pritchard (2004) describe SMI as 'any mental illness that is extremely disabling through its symptoms or its consequences, which are long-lasting'.

2.6 The Impact of SMI on the Family

The onset of a mental illness is a traumatic experience for family members (Johnson, 2000; Kartlova-O'Doherty, Tedstone Doherty, & Walsh, 2006). Trauma can be defined as an experience that is (1) sudden, unexpected or non-normative, (2) exceeds the individual's perceived ability to meet its demands, and (3) disrupts the individual's frame of reference and sense of safety (McCann & Pearlman, 1990). Family members' first contact with mental health services can be a time of shock, devastation and uncertainty (Kartlova-O'Doherty, et al., 2006). Family members have described the influence of SMI, on the family in general, as "an emotional blow" and have reported experiencing constant worry, helplessness, anxiety and stress (Kartlova-O'Doherty, et al., 2006). Efforts to deal with a mentally ill family member can arouse especially strong emotions because people suffering from SMI pose such distinctive threats to the order and coherence of daily life (Karp, & Tanarugsachock, 2000). Marshall, Bell, and Moules, (2010) assert that mental illness is a family experience—shared together, but suffered separately. Empirical evidence clearly shows that chronic trauma, such as SMI, impacts family members and multiple family subsystems (Karp, 2002; Marsh, Lefley, & Husted, 1996). Mental illness can have implications for the way the family functions as a whole, impacting upon core activities such as communication, relating to other members and role performance (Pilowsky, Wickramaratne, Nomura, & Weissman, 2006).

Once it becomes clear that the illness is chronic, and if family members come to believe that their SMI relative is not assuming adequate responsibility for getting well, the kinder emotions of sympathy and concern typically become worn down and darker feelings of

frustration and resentment arise (Karp & Tanarugsachock, 2000). Spouses of those with SMI have reported feeling anxiety, frustration, shame, guilt, worry and grief (Kahn, Coyne, & Margolin, 1985; Wynaden, 2007). Children that have siblings with SMI have reported experiencing frustration, stress, and feelings of guilt and embarrassment in relation to their unwell siblings (Greenberg, Kim, & Greenley, 1997; Sin, Moone, Harris, Scully, & Wellman, 2012). Siblings have also expressed feeling fear of the illness and fear of themselves, or their children, becoming affected (Ewertzon et al., 2012; Schmid et al., 2009). Much of the literature has focused on the impact of having a parent with SMI. Having a parent with SMI can involve a chaotic family life where relationships become strained, and adult children assume substantial caregiving roles (Foster, 2010). Patterns of abuse and neglect by parents with SMI have been identified (Foster, 2010; Ulzen & Carpentier, 1997). Children of parents with SMI are at risk of developing their own mental health concerns (Foster, McPhee, Fethney, & McCloughen, 2016; Saunders, 2003; Walton-Moss, Gerson, & Rose, 2005), and of being overwhelmed by their parent's SMI, and losing their individual sense of identity (Murphy, Peters, Wilkes, & Jackson, 2016). A recent systematic review (Yamamoto & Keogh, 2017), of the experiences of children who were affected by parental mental illness, highlighted the distress, isolation and loneliness that these children experienced. Studies suggest that adult children may experience ambivalent relationships and explosive anger from parents with SMI (Alpert et al., 2003, Foster, 2010; Rutter & Quinton, 1984). These findings are in keeping with literature on attachment (Cunningham et al., 2004; D'Angelo, 1986).

2.7 Family Caregivers

Family caregivers make substantial and valuable contributions to patient care and recovery (Kartlova-O'Doherty et al., 2006; Revier et al., 2015), and reduce rates of relapse and the need for inpatient care (Norman et al., 2005). A family caregiver (often termed as an informal caregiver within the literature) is a person who gives regular, ongoing support to an unwell family member without payment for the care given. With the deinstitutionalisation movement, many families have taken on the responsibility of caring for their family members with SMI (Kohn-Wood & Wilson, 2005; Wynaden et al., 2006). Caregivers UK (2008) have estimated that caregivers save the British economy £87 billion per year. However, despite their crucial role, family caregivers often feel marginalised, are not as involved as they would like to be in their relative's treatment, and feel their expertise is over-looked or devalued (Gray, Robinson, Seddon & Roberts, 2010; Lammers & Happell, 2004). Families report deficits and gaps in the services available to them to cope with the stressors that stem from caregiving

(Farrell & O'Connor, 2017). Studies indicate that families have repeatedly stated that they need, but do not get, information about their relative's illness and treatment, assistance with managing illness symptoms and support for their own anxieties and depressed moods (Awad & Voruganti, 2008; Drapalski et al., 2008; Kartlova-O'Doherty et al., 2006; Rose et al., 2004; Sin, Moone, & Wellman, 2005; Winefield & Harvey, 1994).

2.8 Caregiver Burden

The term caregiver burden is used to convey the cumulative stress experienced by family caregivers. The concept of caregiver burden is well established and has become an integral part of treatment programmes and policy decisions. Despite this, as discussed above, caregivers continue to struggle without adequate support or resources (e.g. Awad & Voruganti, 2008; Drapalski et al., 2008). Caring for individuals with SMI in the community carries a heavy burden for family members (e.g. McCann et al., 2015; Saunders, 2003; Walton-Moss, Gerson, & Rose, 2005). Families experience caregiver burden objectively, through strained relationships, diminished financial resources and the complexities of treatment management for their loved one, and subjectively, through multifaceted emotional responses to a challenging and unpredictable illness (Kealey, 2005). Caring for an individual with SMI can have significant undesirable effects on one's ability to manage one's own life, manifesting as psychological distress, including grief, anger, depression, and anxiety (Bailey & Grenyer, 2013; Zauszniewski & Bekhet, 2014). Grief is an extremely important and pervasive aspect of family caregivers' overall responses to mental illness (Rose, Mallinson, & Gerson, 2006). This is especially true for close family caregivers, who experience a poorer sense of wellbeing that in turn affects the wellbeing of the person with mental illness (Jungbauer & Angermeyer, 2002; Rudnick, 2004), creating a vicious circle and more and more tension and strain for family caregivers. Emotional contagion and the transmission of negative mood and depressive symptoms between patients and family caregivers have been well documented (Knoll et al., 2009; Moser et al., 2013).

By focusing on the mental illnesses of the people they care for, caregivers can neglect their own social networks leaving them isolated (Rose et al., 2002). Caring can adversely affect other family relationships (McCann, Lubman, & Clark, 2009; Stjernsward & Hansson, 2014), causing further stress and strain. Family caregivers and relatives of people with SMI are at greater risk of psychiatric morbidity, lower health-related quality of life and stress-related illness than the general population (Chang & Horrocks, 2006; Chiu et al., 2006;

Hastrup et al., 2011). Caregivers of those who are either partners of, or children of care recipients, appear to be at particular risk (Hastrup et al., 2011). People with mental illnesses often treat their caregivers with hostility instead of appreciation (Karp, 2002). Family caregivers have reported experiencing violence and victimisation within the caregiving relationship, and have expressed fear in relation to their SMI relative (Kageyama et al., 2015; Onwumere et al., 2018).

Over time, the associated stress is linked with increased risk of relapse for the person with illness and weakened family relationships. This, in turn, hinders treatment outcome and pathways to recovery (Baronet, 2003; Perlick, Rosenheck, Clarkin, Raue, & Sirey, 2001). Caregiver's psychological appraisal, and coping style, are influential in determining High Expressed Emotion (EE) which refers to criticism, hostility and emotional over involvement. Research has shown that high EE is associated with discord in relationships between SMI patients and those in caregiving roles, reduced compliance with medication (Sellwood, Tarrier, Quinn, & Barrowclough, 2003) and is a robust predictor of clinical outcomes and relapse in people with psychosis (Barrowclough et al., 2003; Butzlaff & Hooley, 1998; Patterson, Birchwood, & Cochrane, 2005).

Female relatives of persons with SMI report a greater burden than their male counterparts, on their quality of life (Fleischmann & Klupp, 2004). Females tend to provide more personal and instrumental care than males and are at greater risk for psychiatric morbidity (Miller & Cafasso, 1992; Yee & Schulz, 2000). In addition, female caregivers are more likely to report impaired wellbeing (Lutzky & Knight, 1994). Guilt feelings can be attributable to self-blame (McCan, Lubman, & Clark, 2009). Family caregivers can struggle to come to terms with, or reconcile, the dissonance between their past and present relationships and roles (Byrne, Orange, & Ward-Griffin, 2011). The realisation that mental illness may be a permanent condition can provoke emotions of anger and resentment within family caregivers (Karp & Tanarugsachock, 2000). Family members may mourn for the person their loved one could have been, experience fear of the illness, experience guilt about being healthy and enjoying themselves, and fear their own vulnerability to mental illness (Lukens, Thorning, & Lohrer, 2004). Further challenges can include being faced with incomprehensible behavior that may be bizarre or frightening (Karp, 2001; Marsh, et al., 1996; Onwumere, Parkyn, Learmonth, & Kuipers, 2018).

2.9 Stigma

Studies have shown that much of the burden and stress experienced by family caregivers of relatives with SMI, is due to the associated stigma they experience (e.g., Grandón, Jenaro, & Lemos, 2008; Rose, Mallinson, & Gerson, 2006). Stigma can be understood as severe social disapproval due to believed or actual individual characteristics, beliefs or behaviours that are outside norms (Heatherton, 2003). Stigmatisation occurs at an individual, as well as, on a societal level. Research shows that the public generally holds negative views of people with mental illness (Lauber et al, 2000; Rose et al., 2011; Singh, Mattoo, & Grover, 2016). The anticipation and experience of being stigmatised in one's everyday life introduces a variety of negative consequences, including social isolation, impaired quality of life, low self-esteem, and feelings of shame and hopelessness (Link & Phelan, 2013; Rüsch, Angermeyer, & Corrigan, 2005). While stigma clearly adversely affects the quality of life of people with SMI (Mathias et al., 2015), it also substantially impacts on their family members (Gatsou, Yates, Goodrich, & Pearson, 2017; Yin et al., 2014). Due to stigma, family members can experience social isolation, occupational restrictions, frustration, anger, grief, shame, anxiety, low self-esteem, helplessness, reduction in leisure activities, experiences of discrimination, and worry about the future (Grandón, Jenaro, & Lemos, 2008; Rose, Mallinson, & Gerson, 2006; Tsang, Tam, Chan, & Cheung, 2003).

2.10 Self-stigma

Individuals with SMI, and their family members, can experience self-stigma which is insidious by nature. Self-stigma refers to the process of internalising public stigma (Corrigan & Watson, 2002; Yanos, Roe, Markus, & Lysaker, 2008), which often leads to a stigmatised view of oneself (Yanos et al., 2008). Self-stigma is socially constructed through stereotyping, prejudice, and discrimination (Corrigan, Rafacz, & Rusch, 2011; Corrigan & Watson, 2002) and leads to individuals being harmed when they apply these concepts to themselves. Studies have shown that family members of people with SMI are subject to stigma ''by association'' (Phelan, Bromet, & Link, 1998; Struening et al., 2001) and often internalise this (Zisman-Ilani et al., 2013) and experience guilt and shame (Angermeyer, Schulze, & Dietrich, 2003; Karnieli-Miller et al., 2013; Ohaeri & Fido, 2001; Shibre et al., 2001). Family caregivers of relatives with SMI, who have self-stigma, may experience stronger distress and perceive a greater sense of burden during the caregiving process. They may feel shameful for having a family member with SMI while obliged to take care of their relative. Thus, these caregivers

may be subjected to complex feelings of strain and distress, as a result of their relationship to their discredited relative, and due to their caregiving role (e.g. Phelan et al., 1998).

2.11 Resilience

As can be seen from the literature reviewed, caring for a family member with SMI is a demanding task, which can lead to caregiver burden. However, family caregivers also experience resilience, which provides a buffering effect to caregiver burden (e.g. Ong et al., 2018). Resilience is generally defined as a capacity to overcome adversity, or to thrive despite challenges or trauma. The concept of resilience has become increasingly employed in research, which relates to the ways in which individuals, families and communities recover from trauma (Black & Lobo, 2008; Luthar, Cicchetti, & Becker, 2000). Resilient abilities are not simply innate, but can be learned and cultivated. In developing resilience, individuals, as well as families, can not only cope with adversity, but can also become stronger and better equipped to deal with future challenges. They can emerge with growth that has been forged through adversity (Walsh, 2012).

Family resilience incorporates a systemic, or relational, view of resilience. Family resilience refers to relationship processes that may help a family unit to be a source of support to each family member, which may help, or hinder, all individuals within that unit to cope with major difficulties (Cohen et al., 2011; Kalil, 2003; Power et al., 2016; Walsh, 1996). From a family resilience perspective, a family is regarded as a unit with intrinsic strengths and resources, and potential for growth (Black & Lobo, 2008; Zauszniewski, Bekhet, & Suresky, 2009), with positive relational bonds and connections between family members being integral to maintaining their ability to weather adversity (Walsh, 2006). Individual and family resilience are dynamic states that can fluctuate over time, and are developed and maintained through protective factors. Those protective factors are able to modify, or improve, the individual's and family's response to risks that might have otherwise predisposed them to a negative outcome (Ungar & Lerner, 2008).

2.12 Resilience in Families Caregivers

Strong protective factors can bolster a caregiver's resilience, and protect against caregiver burden. Several studies have identified protective factors associated with resilience in families in which a member has been diagnosed with a mental illness. Identified resources include: community support (Anuradha, 2004, Bishop & Greeff, 2015; Enns, Reddon, &

McDonald, 1999), emotional support (Anuradha, 2004; Enns et al., 1999, Greeff et al., 2006) and open and affirming family communication (Anuradha, 2004; Bishop & Greeff, 2015; Enns et al., 1999, Gatsou et al., 2017; Jonker & Greeff, 2009). Social support has been found to reduce psychological burden in caregivers and foster resilience (Ozbay et al., 2007). Perceived social support was found to mediate the association between resilience and caregiver burden (Ong et al., 2018). The capacity to speak openly about mental illness within a therapeutic space may foster resilience because it is a means through which family members can process their grief, and are provided with an emotional holding for both hope and hopelessness (Flaskas, 2007; Joseph, & Linley, 2005; Power et al., 2016). A number of personal qualities indicative of resilience have also been identified, including psychological well-being (Pinquart & Sorensen, 2004), personal control (Atienza, Collins, & King, 2001), coping skills (Doornbos, 2002; Gottlieb & Rooney, 2004; Lim & Ahn, 2003), and hope/optimism (Bland & Darlington, 2002; Tusaie & Patterson, 2006).

Resilience is strengthened by practising regular self-care (Skovholt, Grier, & Hanson, 2001). Self-care is vital for caregivers. A decline in a caregivers' personal wellbeing has undesirable implications for the continuation of their caring role (Byrne et al., 2011). Caregivers have identified the deliberate efforts they make to maintain their own wellbeing, which include physical activities, socialising, and in some circumstances obtaining professional counselling to strengthen their resilience so that they can continue to cope with the demands of being a caregiver (McCann et al., 2015; Zauszniewski et al., 2009).

2.13 Post-Traumatic Growth

The construct of "post-traumatic growth" (PTG; Tedeschi & Calhoun, 1995) proposes that, as a result of trauma, an individual can experience a feeling of growth which goes beyond the previous level of functioning and awareness. As a result of PTG**,** people can change their views of themselves; for example, they may have a greater sense of personal resilience, increased self-worth, strength, and wisdom. Those who experienced PTG have reported that their relationships are somehow enhanced and that they feel increased compassion toward others (Joseph & Linely, 2005; Rosenbach & Ronneberg, 2008). The greater the distress experienced, the greater the possibility of a personal growth since the traumatic event completely upsets the inner world of the individual (Duncan et al., 2007; Salsman et al., 2014; Tedeschi, & Calhoun, 1995). Supportive relationships are important in predicting development in PTG (Barsakova & Oesterreich, 2009). Barsakova and Oesterreich (2009) argue that the

availability of emotional support, may provide opportunities to disclose anger and fear, and in this way facilitate adjustment to traumatic illness-related experiences and PTG.

2.14 Differing Needs and Preferences of Family Members

Based on the literature reviewed, it is evident that family caregivers are significantly impacted by their family members' SMI. However, it is important to note that the needs and preferences of caregivers for people with SMI are diverse and change over time. Duration of mental illness may influence family need (Linszen et al., 1996; Nugter et al., 1997; Solomon, Draine, Mannion, & Meisel, 1996). Family members of those experiencing an emergence, or reemergence, of symptoms typically require introductory psychoeducational information and general support (Glynn, Cohen, Dixon, & Niv, 2006). In contrast, families of individuals with a longer history of illness have already acquired knowledge, have developed some coping skills and often report the need for more targeted information, on aspects such as planning for future care in their absence (Hatfield & Lefley, 2000; Lefley & Hatfield, 1999). A more tailored approach to meet the families' needs is required (Drapalski et al., 2008; Jewel & Smith, 2007).

2.15 Peer Support

Peer support in the mental health field can largely be seen as a process of giving and receiving support, founded on the key principles of respect, shared responsibility, and mutuality (Mead, 2003; Solomon, 2004). Peer support is rooted in the idea that people who share similar experiences can offer help, empathy, validation, information and hope (Mead & Macneil, 2006). Essentially, the peer support 'approach' is one which assumes that people with similar experiences, can better relate and can consequently offer more authentic empathy and validation (Mead & Macneil, 2006). Consistent with social modelling theory, which states that similar others might have the most influence on behaviour change, peer supporters are in a unique position to help (Bandura & Walters, 1977). Peer supporters can offer systems knowledge and can teach successful coping strategies (Carlson, Rapp, & McDiarmid, 2001).

Peer support promotes a wellness model that focuses on strengths and recovery, rather than a medical model, which places more emphasis on symptoms and problems of individuals (Mead & Macneil, 2006). Peer support shifts the focus towards a social model which is aware of the environmental, cultural and attitudinal barriers to inclusion faced by people with impairments and towards the ways in which people with a commonality of experience can support one another to overcome those barriers. Peer support is positively related to self-esteem and moderates the negative association between stigmatisation and self-esteem

(Verhaeghe, Bracke, & Bruynooghe, 2008). Peer supporters who are employed by services are generally considered to be further along their road to recovery, and therefore in a stronger position to contribute (Davidson, Chinman, Sells, & Rowe, 2006).

2.16 The Use of Peer Support in Mental Health Services

Over the past number of decades, peer support services have grown to become an integral component of mental health services, which are evolving towards a recovery-oriented, person-centered system (International Association of Peer Supporters, 2015; Kaplan, 2008; Kaufman et al., 2014; Slade et al., 2014). The increase in the published research on peer-delivered services in general, is evidenced by the recent conduct of several systematic reviews (Cabassa, Camacho, Vélez-Grau, & Stefancic, 2017; Chinman et al., 2014; Fuhr et al., 2014; Lloyd-Evans et al., 2014; Pitt et al., 2013; Rogers, Kash-MacDonald, & Brucker, 2009). Despite having been criticised with regards to methodological rigour and potential bias (e.g. Gillard & Holley, 2014; Lloyd-Evans et al., 2014), the preponderance of evidence has suggested that peer support is an evidence-based practice. However, it has been recognised that additional research is needed to identify the specific circumstances, consumer groups, and attributes of peer support that are most effective (Cabassa, et al., 2017; Chinman et al., 2014; Repper & Carter, 2011). Peer support has the potential to challenge stigma (Davidson et al. 2006; Corrigan, Sokol, & Rüsch, 2013; Keyes & Brandon, 2012; Verhaeghe et al. 2008) and is associated with a variety of positive outcomes, including increased self-efficacy (Mahlke et al., 2017), reduced hospitalisations (Cnaan, & Whitecraft, 1998; Sledge et al., 2011; Trachtenberg, 2013), higher levels of hopefulness for recovery (Cook et al., 2010), improved medication adherence (Magura, et al., 2002), enhanced quality of life (Felton et al., 1995; Klein et al., 1998), and improved social functioning (Kurtz, 1990). Similarly, there is an emerging international body of evidence supporting the effectiveness of peer support programmes for children of parents with mental illness (Foster, Lewis, & McCloughen, 2014; Gatsou et al., 2017; Reupert, et al., 2012).

2.17 Peer Support for Family Caregivers

Family caregivers of a loved one with SMI are only beginning to receive some well-deserved attention in the literature, whereas, family caregivers in other domains, such as for the elderly and those with dementia, have already been recognised as an essential component of care (e.g. National Audit Office, 2007). International studies that have examined the impact of peer support for family caregivers of people with dementia provide evidence of the benefits

of peer support. For example, peer support has been found to lead to increased confidence (Fung & Chien, 2002), and increased perceived quality of life (Charlesworth et al., 2011; Wang, Chein, & Lee, 2012) with evidence of family caregivers feeling more in control (Wang & Chien, 2011). Other benefits of peer support, for family caregivers, include: the impact of identifying with and subsequently engaging with someone in a similar position (including realising that their responses to their situation were 'normal'), reduced isolation, emotional support and release, the significance of enjoying engaging in peer support, learning strategies for managing situations and mutual problem solving (Greenwood, Habibi, Mackenzie, Drennan, & Easton, 2013; Keyes et al., 2016). Taken together, these findings highlight the potential therapeutic effects of peer support for family caregivers of those with SMI. Furthermore, family caregivers of those with SMI, have already reported their need for increased emotional support (e.g. Kartlova-O'Doherty et al., 2006; Rose et al., 2006) and have identified that opportunities for communication with other caregivers, who had gone through similar experiences, would be helpful (Leggatt, 2001).

The existing literature on peer support for family caregivers of individuals with SMI is still very limited. Below, the current published studies on peer support for family members, of those with mental illness, are reviewed.

2.18 Key Study 1: Family-to-Family Education Programme

The Family-to-Family Education Programme (FTF) is a structured, peer-led, 12-week course offered by the US National Alliance on Mental Illness for family members of adults with mental illness. FTF follows a skill-building curriculum and is delivered by trained volunteer family members. The course aims to help family members to develop increased empathy and communication skills, engage in self-care, develop coping and problem-solving skills, understand research that promotes recovery, and access supports and services. Lucksted, Stewart, and Forbes (2008) sought to gather participants' perceptions of the changes they experienced as a result of FTF and to understand what might lead to these changes.

Semi-structured interviews were conducted with 31 FTF graduates. Participants reported experiencing tremendous relief from realising they were not alone and from having the opportunity to talk with others who could relate. Participants reported experiencing reductions in their fear, distress and hopelessness, feeling less alone, increased acceptance, improved self-care, feeling more empowered, and improved coping skills. Participants also reported improved communication, and relationships, within their families. Using constructivist grounded theory analysis, the authors concluded that new factual and emotional

information from FTF shifted participants' understanding of their situation, and that skills acquired through FTF, then allowed them to incorporate these new perspectives into more adaptive behaviours.

2.19 Key Study 2: FTF

These qualitative findings were echoed by findings from a subsequent quantitative study aimed at evaluating the effectiveness of FTF (Dixon et al., 2011). 318 consenting adult participants were randomly assigned to receive FTF immediately, or to wait at least three months for the next class. Participants were assessed on a range of measures at study enrolment and at three months later (at FTF termination) regarding problem-focused and emotion-focused coping, subjective illness burden, and distress. Assessments were conducted via a structured telephone interview. A linear mixed-effects multilevel regression model tested for significant changes over time between intervention conditions. Results indicated that FTF participants had significantly greater improvements in problem-focused coping as measured by empowerment and illness knowledge. Exploratory analyses revealed that FTF participants had significantly enhanced emotion-focused coping as measured by increased acceptance of their family member's illness, as well as reduced distress and improved problem solving. However, the measurement of subjective illness burden did not differ between groups. It is possible that subjective illness burden was not ameliorated by the FTF group educational programme because subjective illness burden is more of a personal and sensitive issue that may be more amenable to addressing, and processing, within a one-to-one therapeutic environment.

2.20 Key Study 3: FTF

Lucksted and colleagues (2013) conducted a 6-month follow-up of this study to determine whether improvements in distress, family functioning, coping and empowerment and reduced anxiety were sustained. Findings revealed that the benefits of the FTF programme were sustained, for at least 6 months, without any additional boosters or supports. This finding suggests that peer-based programmes may produce sustained benefits for individuals seeking help in addressing challenges and stresses related to having a family member with a mental illness.

2.21 Key Study 4: Family Peer Support Helpline

In a study conducted in Israel (Shor & Birnbaum, 2012), 800 phone calls made by family members of persons with mental illness, to a family peer support helpline, were

analysed. An instrument was utilised by the family peers to evaluate and categorise the nature of the 800 calls. In addition, researchers conducted 77 semi-structured follow-up interviews with callers, who agreed to be interviewed, about how they perceived and evaluated the help they received.

Those operating the helpline were family members of persons with mental illness who volunteered to become helpline family peer supporters. The helpline supporters received training regarding how to provide help to callers from two parents who developed and implemented guidelines based upon the knowledge they acquired during their involvement in the helpline since its inception, as well as from their own life experiences.

The most frequent categories of support provided during the 800 calls were emotional support, information and advice. These most frequent categories reveal the callers' main unmet needs. The emotional support sought through the helpline could be understood, in light of the ongoing difficulties families of persons with mental illness may experience, along with the limited support they perceive as received from the formal mental health services. The life experience of the helpline supporters was identified by interviewees as an important characteristic of the helpline. The respondents indicated that the emotional support they received from the helpline supporters, especially during times of crises, and the sense of being understood by family peers were significant and valued features of the helpline. The authors report that a limitation of this study is that they did not investigate whether, or not, there should be any limits on the type of information, advice, or consultation the family peer helpline supporters should supply (it was unclear what type of training helpline supporters received). Another limitation is that the study it did not report on whether the helpline supporters received any supervision. The importance of receiving supervision, while providing therapeutic support, has been well established (e.g. Rakovshik et al., 2016).

2.22 Existing Family Peer Support Programme

The Family Peer Support Worker (FPSW) programme has evolved over a period of years in an early intervention youth mental health service, in Melbourne, Australia (Leggatt & Woodhead, 2016). The FPSW programme evolved in response to feedback from the families, combined with policy directions from Federal and State governments calling for caregiver participation in mental health services. Whilst the FPSW programme is now well established, it has not yet been properly evaluated.

Leggatt and Woodhead (2016) report that in 2009, a small unpublished quality assurance project was conducted, which entailed a brief analysis of the notes written by

FPSWs. 86 cases were examined. The aim was to identify the areas that FPSWs, and families, commonly talked about. The findings showed that FPSWs most commonly spoke with mothers. Providing emotional support for distress was a common theme. There were also questions relating to understanding and managing behaviours, along with discussions around medication. Families welcomed and expressed a need for emotional support, listing a range of negative emotions, including initial shock, frustration, needing to be reassured, exhaustion and sadness. Leggatt and Woodhead (2016) concluded that the FPSW programme appeared to be of great benefit to the families and recommended that the service should be expanded and evaluated to more rigorously determine its specific benefits to families.

2.23 A Traumatised Family Environment

The onset of SMI is a traumatic experience for family members (e.g. Kartlova-O'Doherty et al., 2006; Marshall, Bell, & Moules, 2010). Family caregivers of SMI relatives have reported a family atmosphere of sustained crises and internal conflicts (Rose et al., 2006). A trauma is a biological event, stored in the body, as well as an event the personality struggles to manage (Quillman, 2013). Individuals who have experienced trauma, often experience low integrative capacity and resulting inability to engage in critical thinking and reflective action, which can manifest as constraints in their interpersonal relationships (Siegal, 1999; Steele, Van der Hart, & Nijenhuis, 1997).

Family interactions offer the opportunity to facilitate recovery, but they also have the potential to hinder or impede recovery for individuals with SMI (Aldersey & Whitley, 2015; Brown & Weisman, 2018; Reupert, Maybery, Cox, & Scott Stokes, 2015). The Karpman Drama Triangle (KDT) (Karpman, 1968) maps a type of destructive interaction that can occur between people in drama-intense relationships. The roles are those of rescuers, persecutors and victims. In very simplistic terms, the rescuer is the person who attempts to save others, especially the victim. The persecutor is the person who blames others and tries to keep them in a blameworthy position. The victim is the person who accepts the blame and acts in a helpless manner. The roles within the KDT cannot exist in a vacuum but emerge from relationships with others. The roles are not only relational but highly dynamic with role reversals occurring frequently in some families (L'Abate, 2009).

2.24 Family Recovery from SMI

Based on the literature reviewed, it seems clear that providing adequate support for family members is likely to positively impact on relatives with SMI. In line with Family

Systems Theory, studies have shown that individuals with SMI, who have supportive relationships, are more likely to report a better recovery compared with those who report more stressful relationships (Evert, Harvey, Trauer, & Herrman, 2003; Tew et al., 2012; Thomas, Muralidharan, Medoff, & Drapalski, 2016). Treatment programmes that include family intervention have been found to be more effective than routine psychiatric care alone (Barrowclough et al., 2001). Furthermore, findings indicate that family intervention can lead to long term benefits, such as reduced rates of relapse (Tarrier, Barrowclough, Porceddu, & Fitzpatrick, 1994). It is crucial that family interventions focus on modifying relatives' beliefs at both the cognitive and emotional levels (Tarrier & Barrowclough, 1995). Addressing SMI within the context of the needs, experiences and understanding of the whole family is of central importance but is not well-embedded in practice (Gatsou et al., 2017; Falkov, 2011; SCIE, 2011; Reupert & Maybery, 2014). Programmes that focus on family context and relationships have demonstrated potential to benefit all family members (Fadden & Heelis, 2011; Fallon, 2003), prevent declines in emotional wellbeing, and reduce future costs to health care systems (Reupert & Maybery, 2011).

While there is a growing body of literature on recovery of individuals with SMI (e.g. Drake & Whitley, 2014), there is little information about the recovery process in other family members. In line with Family Systems Theory (Bowen, 1978), family recovery (Spaniol, 2010) has both individual and systemic consequences. recovery for family members, which is a painful process, involves facing the reality of one's experience and its emotional impact, and, readjusting one's attitudes, feelings, perceptions, and beliefs about oneself, others, and life in general. Family recovery involves processing and integrating the trauma, so that one can have a life that includes hope, personal meaning and goals for the future despite the challenges of SMI (Joseph & Linley, 2005; Spaniol, 2010). It entails becoming more aware of how one communicates, and contributes to problematic family dynamics. It also focuses on the importance of practising self-care (Brennan, 2015).

Recovery for all family members is a long-term process with many cycles of despair and hopefulness. Acceptance is a process. It must be remembered that family caregivers are part of the general population which holds stigmatising views about people with SMI (e.g. Singh et al., 2016). Furthermore, these caregivers may also be experiencing self-stigma (e.g. Zisman-Ilani et al., 2013). When family members begin to understand that they too are experiencing a recovery process, this can provide a welcome, more objective, and self-compassionate perspective for them. Gaining this perspective is especially important when family members are caught up in a crisis and it seems as though the pain will never end

(Spaniol, 2010). Following the stress of SMI, it is important for family members to realise they only have control over their personal recovery (Reupert, Maybery, Cox, & Scott Stokes, 2015). The outcome of recovery can be the emergence of a new sense of self that is more empowered, differentiated and empathic (Spaniol, 2010; Reupert et al., 2015). Recovery can give family members a sense of hope about their lives, and the life of their family member with SMI. Even though the illness of their family member continues, family caregivers experiencing recovery have reported feeling differently about themselves; they blame themselves less, are more hopeful, and more accepting of what they cannot change (Lefley, 2008; Spaniol, 2010).

2.25 Policy Background

In reviewing the literature on Family recovery in Ireland, and internationally, it is evident that this is a growing area. Countries such as Australia, New Zealand, Canada and Great Britain have made significant strides towards the development of Family recovery orientated mental health services. The 'Triangle of Care, Caregivers Included: A Guide to Best Practice in Mental Healthcare' (Hannan, Thompson, Worthington, & Rooney, 2013) in England and Australia's guidance document for staff 'A Practical Guide for Working with Carers of People with a Mental Illness' recognise that the service user, mental health staff, and families share a common goal of working towards recovery for individuals with SMI and their family members.

Two of the most important Irish national policy documents on mental health, "A Vision for Change" (Department of Health & Children, 2006) and "Quality Framework for Mental Health Services in Ireland" (Mental Health Commission, 2007), promote Recovery as a guiding principle in terms of service development, delivery and evaluation. "Vision for Change" (2006), states that service users and families should be involved in every aspect of mental health service development and delivery, and that statutory services should put in place peer-led initiatives. According to the HSE Mental Health Division Operational Plan 2017, a major goal in terms of service transformation is to move towards more recovery-oriented ways of working. A key objective in terms of achieving this is to become more centrally informed by the views, and experiences, of service users and family members.

Since 2013, the recovery movement in Ireland has strengthened and has been supported by Advancing Recovery Ireland (ARI). ARI is a National Mental Health Division initiative that brings together people who provide the services, those who use them and their

families, and community supports, to work on how mental health services can be made more recovery-focused.

The National Framework for Recovery in Mental Health, launched on 20th November 2017, builds on the aforementioned polices to develop a more recovery-oriented mental health service. 'Recovery Principle 1', in this document, refers to the importance of, and the need to, engage meaningfully with the family, including the SMI family member. It contends that when services practise in such a way that the person with SMI, and his/her family, are at the heart of designing, delivering and evaluating the service provided, the experience and outcome is better for everyone.

2.26 Current Study

Family caregivers have been recognised as a crucially important community resource for those with SMI. However, the evidence presented in this literature review has shown that not only does SMI impact the whole family, but that providing care to individuals with SMI can have detrimental effects on family caregivers' wellbeing (e.g. Bailey & Grenyer, 2013; McCann et al., 2009; Stjernsward & Hansson, 2014; Zauszniewski & Bekhet, 2014). This in turn can negatively affect the wellbeing, and recovery, of the person with mental illness (e.g. Jungbauer & Angermeyer, 2002; Rudnick, 2004). Family caregivers can also experience resilience, which provides a buffering effect on caregiver burden (e.g. Ong et al., 2018). Providing families with adequate support, which promotes resilience, will not only have long-term cost benefits, but will lead to improved treatment outcomes for those with SMI (Amir, 2016; Norman et al., 2005). In an era of limited resources for mental health care, family interventions need to target, and be responsive to, families'expressed needs.s. However, despite being a rich source of expertise through experience, family caregivers' views are rarely solicited and their voices remain largely unheard (Bradley, 2015).

The Family Recovery Initiatives by Engaging, Networking, and Developing Supports (FRIENDS) project was a pilot initiative that ran from November 2013 to March 2015. The FRIENDS Project was developed from the Mid-West ARI Project, which attempted to meet the unique need for further support, and inclusion, of family members within the Mid-West Mental Health Services. The FRIENDS project was run by a partnership between SHINE (Shine is the national organisation dedicated to upholding the rights and addressing the needs of all those affected by mental illness), the HSE Midwest Mental Health Service, and the Peer Support Centre — Aras Follain. The development of FRIENDS has been informed by the

work of family advocates, empirical evidence, local knowledge and a collective aspiration for a hopeful life for the whole family (Brennan, 2015). The FRIENDS project piloted a model of family recovery and self-care for relatives of people with SMI, in order to enable them to develop the skills and capacity to provide peer support to each other. In line with suggestions for best practice (Kemp & Henderson, 2012; Moran, Russinova, Gidugu, & Gagne, 2013; Repper et al., 2013), a structured training programme was implemented for those training to become peer support providers. Details of this training programme are provided in Chapter 3.

Family Recovery Peer Support (FFRPS) providers are a central element of FRIENDS. These supporters are individuals who have lived experience of supporting a family member with SMI, who have experienced their own recovery processes, and now enjoy a good level of recovery. FFRPS providers are employed in a professional role to use their expertise, and experience, to inspire hope and recovery in others who are in similar situations (Brennan, 2015). FFRPS providers adopt a Person-Centred approach (Rogers, 1951) to developing a relationship, between equals, that is based on the power of shared experience. FFRPS providers bring specific strengths to their work. Among these are life experience, a non-judgmental presence, the development of successful coping techniques and having achieved a good level of personal recovery.

Whilst policy interest in peer support is high, there is, however, a paucity of research on peer support for family members of individuals with SMI. The current study was undertaken in order to address this shortfall in research on peer support for family members of individuals with SMI. Its aims are to explore, and provide informative insights, into family members' lived experiences of receiving FRIENDS Family Recovery Peer Support Intervention, to discuss their evaluation of the intervention and to elicit their views on its effectiveness.

CHAPTER 3: METHODOLOGY

3.1 Chapter Introduction

This chapter begins by providing the rationale behind the decision to adopt a qualitative approach for this research study. Next, Interpretative Phenomenological Analysis, and the rationale underpinning its use in the present study, is discussed. 'Patient and Public Involvement', and how this was incorporated in this study is summarised. A description of the sampling procedures employed by the study, in addition to a detailed description of the individual participants who contributed to the research, are then provided. Next, the specifics of the FRIENDS Family Recovery Peer Support (FFRPS) intervention, including the recruitment, training and supervision of FFRPS Providers are outlined. A comprehensive description of the procedures utilised during data collection, and a presentation on the step-by-step approach used during data analysis, are then given. The chapter closes with a commentary on the management of ethical concerns, trustworthiness and credibility considerations and researcher reflexivity in relation to this research project.

3.2 Rationale for Qualitative Methodology

A qualitative methodology was considered to be the most appropriate means of investigation for the present study, due to the study's aim of gaining a more intensive insight into the lived experiences of family members who received FFRPS (Robson, 2007). The methodology choice was influenced by the fact that FFRPS was a pilot project with only twelve participants. Qualitative research lends itself to understanding participants' perspectives and facilitates exploration into under-researched areas (Elliot, Fischer & Rennie, 1999; Newby, 2014), whereas, within the quantitative research paradigm, inquiry typically proceeds by formulating a hypothesis, which could conceivably be falsified, by a test on observable data. Within the quantitative approach, the frequency of occurrences, or the size of associations between factors, are of particular importance. This necessitates a reduction of experiences to numerical values, in order to utilise statistical analysis techniques (Pietkiewicz & Smith, 2014).

Critical aspects of this study would be at risk of being overlooked with the quantitative approach. While quantitative research has its advantages, it tends to simplify subjective experience and obscure the complexities contained within an individual's experience. A strength of qualitative research is its ability to provide deeper insights into the subjective experiences of individuals, while also highlighting the differing perspectives among the participants under investigation (Flick, 2002). The researcher's ontological assumptions (perceptions about the very nature of being) have influenced her epistemological stance (understanding of the very nature of knowledge), which in turn influenced the methodological approach to this study (Cohen, Manion, & Morrison, 2007). While undertaking this research, a critical realist ontological and epistemological position was adopted. Put simply, the researcher postulates that while experience is always a product of interpretation, and therefore constructed and flexible rather than determined and fixed, it is nevertheless real to the person who is having the experience.

3.3 Interpretative Phenomenological Analysis (IPA)

Various qualitative methods were considered for the present research study. However, Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2012) was selected as the analysis method of choice for a number of reasons. Table 3.1 presents a comparison of IPA with other qualitative methods that were contemplated, but discounted.

Table 3.1
Comparison of IPA with other approaches

Method	Description	Critique	Rationale for Discounting Method
Thematic analysis (TA)	Thematic analysis (TA) is used for identifying, analysing, and reporting (themes) within data (Braun & Clarke, 2006). The method of analysis should be driven by both theoretical assumptions and the research questions. Thematic analysis provides a flexible method of data analysis and allows for researchers with various methodological backgrounds to engage in this type of analysis	Critics argue that reliability with this method is a concern because of the wide variety of interpretations that arise from the themes, as well as applying themes to large amounts of text.	Relative to IPA, TA does not provide the same amount of scope for interpreting beyond participants' spoken words. For example, given the deeply personal nature of the research topic, it was anticipated that the researcher may have had to interpret, and analyse, moments of defensiveness or hidden meanings. Furthermore, the present study seeks to gain insight, and different perspectives, on the same experience, through participants' eyes. As such, it was decided that, using IPA, with its idiographic focus, was the optimum choice of methodology for this study
Grounded Theory (GT)	Grounded Theory (GT) (Glaser & Strauss, 1967) is a systematic methodology involving the discovery of theory through the analysis of data (Martin & Turner, 1986). GT requires the analysis to be directed towards theory development (Holloway & Todres, 2003) in a 'bottom up' approach.	GT is often misunderstood. There is significant disagreement between grounded theorists as to what constitutes GT. Critics argue that it is impossible to free oneself of preconceptions in the collection and analysis of data in the way Glaser and Strauss say it is necessary (Thomas & James, 2006)	Classic GT requires the researcher to re-enter the field, having analysed the first round of data collected and conduct further interviews to address questions arising from previous analysis; a process known as "data saturation". As this study has recruited the only 12 participants who have experienced the FRIENDS peer support, it was not possible to conduct more interviews if necessary, and the researcher's closeness to the world under scrutiny may also constitute a barrier to a classic GT approach. Because this research

			aims to gain insight into the lived experiences of family members who received Peer Support, GT was not considered to be the most suitable choice for analysis.
Discourse Analysis (DA)	Discourse Analysis (DA) first came to prominence after a publication by Harris (1952) and it covers a number of approaches to analyse written, vocal, or sign language use, or any significant semiotic event.	DA takes many forms and includes semiotics, psycholinguistics, and sociolinguistics to name but three. Choices must be directed by the research aims, which may lead to difficult decisions early in the research process (Brown & Yule, 1983)	DA requires a detailed theoretical and technological knowledge of the approach. In addition, this study is not examining language per se as a means of constructing meaning.Thus, DA was not considered to be a suitable choice of methodology for this study.
Narrative Analysis (NA)	Narrative Analysis (NA) emerged as a discipline from within the broader field of qualitative research in the early 20th century (Riessman, 1993). NA uses field texts, such as stories, autobiography, journals, field notes, letters, conversations, interviews, family stories, photographs (and other artefacts), and life experience, as the units of analysis to research and understand the way people create meaning in their lives as narratives (Clandinin & Connelly, 2000)	Critics argue that while NA challenges the idea of quantitative objectivity, it is lacking in theoretical insights of its own (Boje, 2001).	For NA, different manifestations of the method exist, from within a broard theoretical framework, making choice difficult (Murray, 2003). In addition, the study is exploring participants' lived experiences of receiving FFRPS, and is less concerned with the telling of the story but more focused on the story told.

IPA draws upon phenomenology (consciousness and how people understand life experiences), hermeneutics (the study of interpretation) and idiography (concern for the particular) to provide researchers with a framework for understanding how people make sense of their personal and social worlds (Smith et al., 2012). IPA focuses primarily on the subjective meaning of lived experience, which is phenomenological in nature (Lyons & Coyle, 2016). Husserl (1927; 1970), the principal founder of phenomenology, believed that phenomenology involved stepping out of our 'natural attitude' in our everyday experience and adopting a 'phenomenological attitude' which involves a reflexive, conscious attempt to pay special attention to the taken-for-granted everyday experience (Smith et al., 2012). Heidegger (1962) built on Husserl's phenomenological foundations by proposing that phenomenology has both visible meanings and hidden meanings (Smith et al., 2012). Heidegger contends that both the visible meanings, and hidden meanings, require attention during interpretation.

An IPA approach examines a participant's interpretation of their experience, demonstrating its strong hermeneutic foundation. Furthermore, the researcher's own interpretation of the participant's experience is a crucial facet of IPA's hermeneutic stance. Smith and colleagues (2012) referred to this process as a 'double-hermeneutic', whereby the participant is 'making sense' of their experience, while the researcher strives to 'make sense' of what the participant has said. The IPA researcher aims to access the participant's perspective, while acknowledging that he/she does not have direct-access to the participant's 'inner world'. Therefore, it is essential for researchers to be aware of their preconceptions in order to minimise the influence that these will have upon the interpretative process (Smith & Osborn, 2003). However, the researcher may not be aware of his/her own preconceptions, which may only come to light when the researcher enters into a 'hermeneutic circle'. This entails a dynamic and cyclical approach to bracketing and engaging with the data (Smith, 2004).

IPA is idiographic in its approach, which means that it explores an individual's relatedness to a particular event or process, and is committed to capturing the 'particular' in the form of a detailed and in-depth analysis (Smith & Osborn, 2003). An appreciation of context is required in order to examine and gain understanding of experiential phenomena. For example, in order to make sense out of any part of an interview transcript, one has to examine all parts, and consider that part within the entirety. Doing so, constitutes the dynamic, non-linear and reiterative process of IPA (Smith et al., 2012).

Studies employing IPA focus on specific individuals as they deal with specific events in their lives (Larkin et al., 2006). IPA strives to gain an 'insider's perspective' (Condrad, 1988). It proceeds by conducting an in-depth analysis of individual cases prior to formulating more general statements (Pietkiewicz & Smith, 2014). Thus, this idiographic approach to data collection provides the flexibility to allow participants to discuss aspects of their experience, which may not have been anticipated beforehand (Willig, 2008). This potential to discover novel constructs is a strength of IPA (Brocki & Wearden, 2006).

3.4 Patient and Public Involvement

There is a growing acceptance of the need for more patient and public involvement (PPI) in research (e.g. Domecq et al., 2014). The purpose of PPI is so that research can be carried out 'with' or 'by' members of the public rather than 'on', 'about' or 'for' them (What is public involvement in research, 2018). PPI is thought to improve the way that research is prioritised, commissioned, undertaken, communicated and used (Brett et al., 2014**).** Active involvement of service users in research can lead to research of greater quality and relevance owing to the unique perspective that service users can bring to a research project (Chalmers, 1995; Entwistle et al., 1998; Goodare & Smith, 1995). The description of PPI adopted for the present study was: 'PPI is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making' (Rise et al., 2013). The GRIPP checklist (Staniszewska, Brett, Mockford, & Barber, 2011), which aims to enhance the quality of PPI reporting, was adhered to as described in Table 3.2.

Family caregivers (i.e. family members), who had undergone training to become FFRPS providers and who were members of the FRIENDS steering group committee were invited to participate in the development of the present study. The researcher attended five FRIENDS steering group meetings and consulted with the attendees on the proposed research project. d appropriateness of the present study (see details in Table 3.2).The active involvement of family caregivers greatly enhanced the quality, relevance and appropriateness of the present study (see details in Table 3.2).

Table 3.2
The GRIPP checklist (Staniszewska, Brett, Mockford, & Barber, 2011)

GRIPP checklist	Application in the present study
Definition of PPI	The purpose of PPI is so that research can be carried out 'with' or 'by' members of the public rather than 'on', 'about', or 'for' them (What is public involvement in research, 2018). PPI is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making' (Rise et al., 2013).
Aim of incorporating PPI	It was considered important to get family caregivers views and suggestions on how to undertake the present study and their perspective on various proposals covering different aspects of the study.
Description of PPI participants	One male and one female family caregiver, who were members of the FRIENDS steering group committee, and had undergone training to become FFRPS providers.
The detail of the PPI activity	During 5 research meetings with the FRIENDS steering group committee, family caregivers contributed their thoughts and suggestions on the research objectives, recruitment strategy and proposed methodology. They also provided feedback on the initial Information Sheets and interview schedule.
What level of PPI was utilised	Consultation level
Whether PPI occurred at one stage or multiple stages of research,	PPI occurred at one stage, during the initial research design and planning stage.
Capture of PPI Impact	PPI led to family member-focused research objectives, and a more family member-friendly recruitment strategy. PPI assisted in improving the sensitivity of wording in the invitation letters and information sheets (Appendix A & C). It also assisted in adapting research language to suit a lay audience.
Comment on how effectively the definition of PPI adopted in this study has been operationalised.	In keeping with Rise and colleagues' (2013) definition, PPI, in this study, was founded on mutual respect, and dialogue was carried out, aimed at achieving shared decision making, during the initial research design and planning stage. However, PPI was not implemented during the analysis or write up stages.
Comment on the importance of context and process factors.	The researcher undertook to evaluate one strand on an already established, larger project. This meant that relationships, and trust, had already developed among members of the FRIENDS steering group committee. This may have supported the family caregivers in sharing their views and offering feedback.
Comment on how adequately PPI impact has been measured and any key limitations.	PPI impact was not formally measured during this study.

Critical perspective:	PPI enhanced the quality and appropriateness of the present study, and most likely, participation rates from family members (due to the researcher's increased understanding of family caregiver's perspectives, and the improved wording on the invitation letters and information sheets). On reflection, the only drawback of incorporating PPI was that it was somewhat more demanding in terms of time, however its contribution far outweighed this drawback. Due to the sensitivity of the content of the individual interviews, the researcher decided not to incorporate PPI during the analyses or write-up stages due to ethical considerations (e.g. confidentiality issues and because data may have been 'triggering'). The researcher regrets not having designed a simple rating scale for the family caregivers to evaluate how involved they felt in the process and to capture their thoughts on the extent to which they considered it to have been a shared decision making process.

3.5 Participants

3.5.1 Inclusion Criteria

Individuals, over the age of 18, who had a family member referred to the community mental health service, within the previous 18 months.

3.5.2 Recruitment

In keeping with the idiographic nature of IPA, a purposive sampling method was utilised. This entails the conscious selection of participants who can offer an insight into the particular phenomenon under investigation (Smith et al., 2012).

Based upon their established relationships with many family members, it was agreed that the two social workers, from the adult mental health service, were best placed to select and invite family members to participate in the pilot study. The social workers extended the invitation to family members:

a) of service users who were referred to the adult mental health service during the past 18 months and

b) who the mental health team believed, were in need of support.

These family members were informed about FFRPS, provided with an information sheet (Appendix A) and invited to participate. However, many of these individuals declined the offer. Information on available support (Appendix B) was provided to family members who wished for more support but declined to participate in this study. In order to recruit enough participants, the decision was made to extend the invitation to all family members of

service users, who the mental health team believed, were in need of support. Once 12 family members had volunteered, the recruitment was stopped.

3.5.3 Sample Characteristics

A sample size of 12 was decided upon in order to factor in for the typical attrition rate of 33% (Ahern & Le Brocque, 2005). When examining the essence of individual experiences, Smith and colleagues (2012) refer to the advantage of working with a relatively small sample and suggest that four to ten interviews are sufficient for professional doctorate research projects (Smith et al., 2012). Participants were 12 females between the ages of 23 and 69 years of age (mean = 50.58, SD = 13.19). Table 3.3 presents relevant information on the participants, and upon the interviewer's impressions, and experiences, of engaging with each participant.

Table 3.3
Descriptive information in relation to participants

Pseudonym & age of interviewee	**Interview duration**	**Relationship to person with mental illness & living arrangements**	**Family member's diagnosis & length of time in Mental Health Community Service**	**Age of service user**	**Number of FRIENDS Peer Support Sessions attended**
Natalie	71 minutes 17 seconds	Mother Living together	Major Depression 2 years	32 years	6/6
Caoimhe	52 minutes 53 seconds	Daughter Living together	Bipolar Depression 18 years	52 years	6/6
Karen	60 minutes 42 seconds	Partner Living together	Major Depression 2 years	39 years	6/6
Julia	32 minutes 38 seconds	Wife Living together	Major Depression 13 years	47 years	6/6
Martha	60 minutes 1 seconds	Mother Living independently	Bipolar Depression 4 years	35 years	6/6
Mary	65 minutes 34 seconds	Mother Living independently with community support	Schizophrenia & an acquired brain injury 27 years	48 years	6/6
Alice 58 years	47 minutes 59 seconds	Mother Living together	Major Depression 4 years	19 years	6/6

Sarah 37 years	82 minutes 51 seconds	Mother Living together	Depression & Autism Spectrum Disorder 2 years	19 years	6/6
Claire 58 years	70 minutes 56 seconds	Mother Living together	Bipolar Depression 17 years	33 years	6/6
Alison 43 years	52 minutes 52 seconds	Daughter Living together	Bipolar Depression & Schizophrenia 37 years	74 years	4/6
Edie 60 years	108 minutes 21 seconds	Mother Living together	Schizophrenia, paranoia, psychosis 5 Years	27 years	6/6
Leah 47 years	127 minutes 72 seconds	Mother Living together	Depression & Separation Anxiety & Dyspraxia 2 years	20 years	6/6

Average interview length = 69 minute

3.6 Recruitment of FFRPS Providers

Following engagement with relatives at initial wellness workshops, attendees were invited to self-select as prospective FFRPS providers.

3.6.1 Training of FFRPS Providers

In line with suggestions for best practice (Kemp & Henderson, 2012; Moran, Russinova, Gidugu, & Gagne, 2013; Repper et al., 2013), a structured training programme was implemented for FFRPS providers. Interested parties underwent a 7-week structured course, which entailed 49 hours training (from 10am – 5pm, one day per week). The FFRPS Training Course, which commenced in June 2014, was designed, developed and co-produced by members of the FRIENDS Steering Group, SMI relatives and HSE staff. The course design was informed by an extensive literature review and research on best practice nationally and internationally. Reflective learning and sharing of experiences were central in facilitating personal development. Table 3.4 outlines the training course content.

Table 3.4
FFRPS training course content

Session Number	Content	Learning Goals
Introductory Session	What is Peer Support? FRIENDS Project Process Outline of Course Content Supporting Involvement	To introduce the concept of Family Recovery Peer Support To orient participants to the training To support and encourage participation
Values, the Recovery Model and Language of Recovery	▪ What are values? ▪ The Recovery Model and its contrast with the Medical Model ▪ WRAP Personal Bill of Rights ▪ How values are reflected in our language	▪ Naming our values, both individually and as a collective ▪ To examine a Recovery Approach in more depth ▪ To further understanding of rights and autonomy ▪ To examine the importance of language in describing experiences
Lived Experience and Recovery	The Process of Transition What is a recovery journey? Family members' recovery journeys. What is empathy?	To further understand how change affects us emotionally To examine the challenges and benefits of recovery for the family
Empathy	▪ The experience of mental health difficulties ▪ Sympathy Vs Empathy ▪ Person-Centred approach (Rogers, 1951)	▪ To further understand the lived experience of mental health difficulties ▪ To empathise with others in a more meaningful way
Supportive Relationships	Features of a supportive relationship The challenges of supporting someone in a meaningful way. Karpman's Drama Triangle) (Karpman, 1968) Listening in Peer Support	To examine the values underpinning a supportive relationship To identify common pitfalls in supporting someone To examine how we 'listen differently' in Peer Support
Listening and Responding	▪ Intentional Listening – the Five Commitments ▪ Peer Support in Action ▪ Responding in Peer Support ▪ Signposting and Avoiding Advice-Giving ▪ HSE Mental Health Services	▪ To name and examine the skills of Intentional Listening ▪ To role play and practise skills ▪ To introduce relevant HSE Services for family members

3.6.2 FFRPS Intervention

Participants engaged in 6 sessions of FFRPS. These one-to-one meetings, which lasted approximately 1 hour each, took place in pre-booked HSE rooms at agreed times that were convenient for both participants and FFRPS providers. Each FFRPS provider had a case load of approximately 4 family caregivers. They received a wage for the service they provided.

3.6.3 Supervision

While providing these interventions, each FFRPS received 1 hour of individual supervision each month (6 hours in total) in addition to 2 hours of group supervision each month (12 hours in total).

3.7 Instruments

- A dictating machine
- Participant Consent Form (Appendix C)
- Semi-structured Interview Schedule (Appendix E)
- Participant Debrief Form (Appendix F)
- NVivo (QSR International Pty Ltd. Version 11, 2015).

3.8 Interview Schedule

A semi-structured interview schedule (Appendix E) was constructed prior to the commencement of data collection. Open ended questions were developed in accordance with the conventions recommended by Smith and colleagues (2012) and were informed by the research study's aim of gaining insight into participants' lived experiences of receiving FFRPS. The schedule was reviewed by the study supervisor. Typical questions (or prompts) included 'Tell me about your experience of having a family member suffer with mental illness?', 'How did it impact the family?' 'Tell me about your experience of receiving FFRPS?'.

3.9 Ethical Considerations

Ethical approval for the present research study was received from the relevant local ethics Committee (Appendix J). The application process prompted the researcher to consider, and pre-empt, relevant ethical issues. Planning, and decisions made, were guided by the Psychology Society of Ireland (2011) 'Code of Professional Ethics'. As previously outlined, informed consent was obtained. After having completed the FFRPS intervention, and prior to commencing the interview, participants were asked to read the Information Sheet and sign the Consent Form. To allow for possible pre-interview nerves, which could interfere with assimilating the content of the Information Sheet, participants were provided with this information verbally by the researcher. Participants were reminded of their right to withdraw participation beyond the cessation of the interview, without fear of consequence. Participants were encouraged to ask any questions they may have had.

3.9.1 Confidentiality and Identity Protection

It was explained to participants that, in the write up of the study, they would be assigned pseudonyms, and identifying information would be removed, to protect their identities. Participants were assured that only the primary researcher would have access to the coding key, which documents participants' real names and pseudonyms.

Limits to confidentiality in relation to maintaining safety of participants, and others, was verbally explained prior to commencing the interview. After each interview, the dictating machine audio file was transferred to a password-protected computer, with audio files encrypted and password protected. Each audio file was then deleted from the dictating machine. All back up recordings, made on the researcher's phone, were also deleted. Transcripts were reviewed solely by the primary researcher, with the exception of one sample transcript review, conducted by the supervisor, for the purpose of inter-rater reliability.

3.9.2 Potential Distress

The researcher was mindful of the potential for distress during data collection, as well as in the aftermath of participation. The researcher remained sensitive to this throughout the interview process. Participants were invited to signal at any point if they wished to have the dictating machine switched off.

Following participation, participants were provided with a verbal debrief in addition to the Debriefing Sheet, which contained contact details for further support following participation, if required. It also contained the researchers' contact details so that the participant could contact the researcher, if so desired, following participation.

3.10 Procedure

3.10.1. Pilot Study

The purpose of a pilot is to identify any problems that could arise, and to adapt accordingly (Remenyl, 2012). A pilot interview was conducted with a friend who has engaged in personal therapy due to family stressors and addiction within the family. This pilot interview was used to test how the prepared questions might be received. It also highlighted issues that needed to be resolved prior to conducting the interviews. On the basis of this pilot, adjustments were made to the order of questions and certain word choices (Appendix G).

3.10.2. Data collection

Nine of the interviews were conducted on the researchers' University campus, in a pre-booked private room. Two further interviews were conducted in pre-booked HSE offices, at locations that were more convenient for the participants. In accordance with one participant's request, one interview was conducted and recorded over the phone. Interviews were conducted between one and three months after participants had completed the FFRPS intervention.

Interviews were recorded, with permission from each participant, using a dictating machine. The telephone interview was recorded using the 'Boldbeast' android call recording app. Backup recordings were made using the 'Voice Recorder' phone app. Immediately after each interview, the recordings were uploaded to the researcher's computer and the original recordings were deleted. The interviews generally proceeded in the following manner: The researcher began by attempting to put the participant at ease, answered any questions they had, provided them with tea/coffee/water and began developing a rapport. Next, the researcher explained the purpose of the Consent Form (Appendix C) and encouraged participants to read it before signing. Participants were reminded of their right to withdraw then, without fear of consequence. Permission was then sought to audio record the interview using a dictating machine. Participants were invited to signal at any point

during the interview if they wished to have the dictating machine switched off.

During interviews, the schedule was used flexibly. Participants were all invited to share their experiences of receiving FFRPS, and were then provided with a lot of room to do so. A process of reflecting and probing was adopted. The interviews lasted between 30–127 minutes, with the average duration being 69 minutes.

3.11 Reflexivity

Reflexivity is considered an integral component of IPA (Smith et al., 2012). A project which explores human experience benefits from, and even demands, reflexivity (Shaw, 2010).The IPA researcher is required to observe, and note, his/her own presuppositions, biases, values, beliefs and judgements etc. Doing so, is intended to minimise the impact of the researcher's biases on the data collection and analysis (Smith et al., 2012). What the researcher brings to an IPA study, by virtue of being human, may have either a facilitative, or hindering, influence on each phase of the research process, and upon the quality of the IPA analysis (Smith, 2004). Engaging in reflexivity during analysis helps researchers to navigate their way through the participant's account, and their responses to it.

In the present study, the researcher was very mindful of how she was drawn towards volunteering to research this pilot intervention and how, as a Psychologist in Clinical Training, and as a person who has engaged in personal therapy, she is biased in favour of therapeutic interventions. The researcher also has a family member who experienced a period of mental illness. The researcher was conscious that her personal biases may, unwittingly, influence her application of the IPA analytic process. For this reason, striving to generate a transparent audit trail (e.g. Appendix K, M, N), and implementing provisions, such as credibility and trustworthiness checks (Table 3.5) were considered vital. Reflective journaling (Appendix H) throughout the project also increased the researcher's awareness of personal motivations, biases and opinions. Reflective entries were written after each interview; these supported the analysis stage of the project.

Table 3.5
Elliott, Fischer, & Rennie's (1999) guidelines and Yardley's (2011) core principles for evaluating the validity of qualitative research

Quality Criterion: Elliott, et.al. (1999) guidelines	**Quality Criterion:** Yardley's (2011) core principles	**Provisions made by researcher**
Situating the sample	**Sensitivity to context**	• The researcher reviewed the relevant literature, and spoke with friends who have family members with mental illnesses, in order to increase her sensitivity towards participants' circumstances/context. • From having completed a six month placement on an adult mental health community team, the researcher had some familiarity with the general culture, and workings, of a community mental health team. • Good working relationships were formed with community mental health team's social workers based upon a number of meetings and regular communication. It was decided that the social workers, due to their established relationships, were best placed to offer FFRPS to family members. When the researcher met with participants, having a common ally seemed to assist with the initial development of rapport and trust. • The researcher familiarised herself with the central concepts intrinsic to IPA prior to developing the interview schedule and commencing data collection. • The researcher demonstrated reflexivity by considering how she may potentially, and may have, influenced participants' actions. For example, careful consideration was put into the recruitment process, information sheets (Appendix A), consent forms (Appendix C) and reflective notes were kept following communication, and engagement, with participants (Appendix H).

		• The researcher was cognisant of the power imbalance in an interview situation between a researcher and a participant. In an effort to reduce this power differential, the researcher took a number of steps. For example, the intent of the research, and the rationale for conducting it, was clearly communicated to participants. It was clearly explained that pseudonyms and non-identifying information would be used so as to protect their identities. Prior to the interview, participants were informed of the main question that would be asked. Before the interview, participants were reminded of their right to withdraw. During the interview, participants were invited to let the interviewer know, at any point, if they would like to stop or to take a break or have the dictating device turned off. • Intensive immersion and prolonged engagement with the interview data occurred.
	Commitment & Rigour	• Strategies (e.g. being fully present and congruent) were employed to encourage/facilitate participants to share honestly of their experiences. • The researcher attuned to each participant and, adapted to, and remained aware of, participants' needs throughout the data collection process. For example, the interviewer only scheduled a maximum of two interviews per day as it became apparent that the interviews demanded a lot energetically in terms of presence and emotional availability. Furthermore, some participants took up to two hours to relay their experiences. • Existing literature was examined in order to frame the current findings. • Strategies were used to ensure that data was provided only by those who were genuinely willing to take part and prepared to offer data freely (e.g. many opportunities to refuse to participate were provided; an extended recruitment period of 4 months was allowed).

Owning one's perspective		• Participants were repeatedly reminded that there was no 'right' or 'wrong' answers and that the purpose of the research, was so that they could inform/teach us about their lived experiences. • Reflective notes were kept to record the researcher's initial impressions of each data collection session, patterns appearing to emerge in the data collected and theories generated (Appendix H). • Reflective journaling throughout the project increased the researcher's awareness of personal motivations, biases and opinions. Doing so, assisted the researcher to think, and write, critically. • Literature review was conducted to establish the context of study, and detailed descriptions (e.g. of participants, methodology) were provided to allow comparisons to be made. • A commitment to IPA, and sensitivity to context, remained important during the analysis phase. The researcher strived to conduct a detailed idiographic analysis of each interview before concentrating on the themes emerging across interviews. • Regular supervision was availed of, which provided a sounding board for the investigator to test her developing ideas and interpretations. Probing and feedback from others helped the researcher to recognise her own biases and preferences. • The researcher presented the project proposal to peers, experienced academics, and the community mental health team and incorporated feedback and suggestions. • The researcher attended IPA workshops facilitated by an IPA specialist.

		• The researcher sought a review from an independent IPA consultant, which helped in the final identification of themes and interpretation. • The supervisor conducted a validation check on the accuracy of transcriptions, the appropriateness of initial notes and emergent themes, and upon the conceivability of the interpretations drawn. Inter-rater reliability is used by qualitative researchers to ensure dependability of the data analysis. • Initial findings were presented to the psychology department while on placement which enhanced the analyses.
Situating the sample		• In keeping with Maykut and colleagues (1994) recommendations, biographical information, pertaining to the researcher, which was pertinent to the study, was reported upon.
Providing credibility checks		• 'Thick' descriptions of the interviews are provided. For example, significant pauses, tears, whispers and laughter, and the interviewer's experience was reported upon to convey the emotional climate of each interview. Such detailed descriptions promote credibility as they help to convey the actual situations that have been investigated and, to an extent, the contexts that surround them. • The study's findings are discussed in relation to previous research to assess the degree to which the project's results are congruent with those of past studies. • In line with Smith and colleagues' (2012) recommendation, a purposive sampling method was used and the study's sample size was considered adequate to address the research question.

Coherence **Grounding in examples** **Resonating with readers** **Accomplishing general vs. specific research tasks**	**Transparency & Coherence**	• There is a clear coherence across the research aims, the philosophical perspective, the methodological and analytical approaches to the present study. • The decision to use NVIVO was made so that the research could clearly and transparently demonstrate the audit trail (Appendix K, M, N). • In-depth methodological descriptions are provided to allow the study to be repeated. • Direct extracts are presented in the results so that participant's voices can be heard directly, and so that readers can discern for themselves the patterns identified. These extracts were carefully weaved into the researcher's IPA analysis to aid transparency and substantiate the proposed interpretations. • Extracts of the IPA data analysis are presented in Appendix I. • Reflexivity - the researcher reflected on her own perspective and the motivations, and interests that shaped the research process (from formulation of the research question, through method choices, analysis and interpretation). • Attempts were made to demonstrate both the individuals' and the group's experience by intertwining each person's account; comparing and contrasting when relevant.
	Impact & Importance	• Currently, there is a paucity of research on peer support for family members of individual's with SMI. The findings from this study provide valuable insights into family members' lived experiences of receiving FFRPS Intervention.

	Impact & Importance	• The findings from this study provide evidence that FFRPS is a beneficial intervention. • The findings also provide very important, and needed, practical recommendations based upon family members' suggestions.

3.12 Data analysis

After the interview data was transcribed verbatim; each interview transcript document was reformatted in Microsoft Word to aid the IPA analytical process. As recommended by Smith et al. (2012), three columns were used during the analysis: the middle column contained the original transcript text, the left column contained space for emergent themes and the right column contained space for exploratory comments (please see Appendix I for an example). These comments included descriptive, linguistic and conceptual notes.

The researcher followed the procedures outlined by Smith and colleagues (2012) when completing the analysis. As IPA is an iterative process that is characterised by an inductive cycle, the analysis took place over an extended period of time. The researcher would read transcripts, leave them aside before returning to them again sometime later. The analytical stages, which the researcher progressed through, are outlined in Figure 3.1. Many themes emerged within individual transcripts and when the same themes appeared in at least half of the other transcripts, they were categorised as recurrent. This was to promote an idiographic perspective but, at the same time, to counterbalance that perspective with more generic accounts across the transcripts. Capturing the meaning of the phenomenon (to the participant) was central but this necessarily involved interpretative engagement with the text (Smith et al., 2012). The researcher also sought a review from an independent IPA consultant, which helped in the final identification of themes and with interpretation.

3.12.1 Using NVivo Data Management Software

It must be stressed that, when using qualitative data management software, such as NVivo, the researcher does not relinquish the hermeneutic analytical task to the logic of the software programme. The software is simply enlisted as a tool to aid transparency, and can support efficiency and organisation during the coding process. Qualitative data analysis software itself, cannot conduct analysis or draw interpretations. Using NVivo can provide the researcher with a clear audit trail (e.g. by generating a codebook).

3.12.2 IPA Applied - Phases and Steps Taken in the Analytical Process

Eight discrete cycles of analyses were conducted across the iterative process of data analysis. These cycles involve three separate cycles of coding, two cycles of managing codes, one for initial categorisation of open codes, one for data reduction through consolidating codes into a more abstract theoretical framework (superordinate themes) and one which uses writing itself as a tool to prompt deeper thinking of the data (Bazeley, 2009), leading to findings from which conclusions may be drawn. Table 3.6 outlines how these cycles and processes conducted in NVivo map onto the practical guidelines for data analysis and interpretation, as set out by Smith and colleagues (2012).

Table 3.6

How the cycles phases and processes conducted in NVivo map onto the practical guidelines for data analysis and interpretation, as set out by Smith et al. (2012)

IPA analytical focus (Smith et al., 2012)	NVivo Process
Steps 1 & 2*: Familiarisation with the interview transcript & initial coding:* Reading and initial noting, complete immersion in the original data (interview transcripts). To attend to the participant, and focus on the sense and meanings they make about their experiences – hopefully moving from the broad and general to specific details about events. Initial noting examines language use and semantic content. Three main processes are involved: 1. Descriptive comments on the content of the transcript 2. Linguistic comments on how the participant has used language 3. Conceptual (interrogative and reflexive) comments to start interpreting the text.	**Open coding** As far as possible the participant's own words (from the transcript) are used to summarise the sense or meaning that he/she is trying to convey about a specific experience. Open codes ('nodes' in NVivo) are created for the participant's transcript. Codes aim to make a first pass at reducing the original data to descriptive phrases and notes. This is an iterative process – going through each transcript several times to code and re-code and to add comments, both interrogative and reflexive as follows: 1. Code Names capture the summary overall description of the content 2. Rich descriptive comments to provide coding transparency are included in the Code Description. 3. A journal captures reflexive and conceptual comments arising from the interview.
Step 3: *Interpretative coding & developing emerging themes:* At this stage, the researcher performs a deeper analysis, applying psychological concepts and different interpretative lenses to the data.	**Category creation (subordinate themes)** As the first step in data reduction, a new 'Category' folder for the participant's transcript in NVivo holds a copy of the set of open codes, so leaving the original open codes folder for the participant intact. Then reviewing each code in the category folder, reordering codes into broad categories (codes are added to other codes either as parent or, more usually as child codes), merged, and re-named, ensuring that new names accurately reflect coded content to allow a more in-depth understanding of the participant's lifeworld.

Step 4: *Searching for connections across emergent themes:* The researcher attempts to reduce the volume of data (by summarising) while retaining its complexity by looking for patterns and connections. The hermeneutic circle (Heidegger, 2012) concerns interpreting the part of the transcript in relation to the whole and the whole in relation to the part. Themes should be a synergistic process of description and interpretation reflecting both the participant's original words and thoughts; and the researcher's interpretation.	**Category Development (Superordinate themes)** Employing IPA strategies to create superordinate themes for clusters of codes. The first step is to consider how categories may be linked or reduced further into emergent themes. New names are created for category themes that reflect both the descriptive and the interpretative to create 'superordinate' themes
Step 5: *Moving to the next case* The same process outlined above is followed with the other interviews. Reflecting on the analysis leads to the connection of emergent themes to form subordinate themes for each interview. An idiographic approach is taken where each interview is analysed and coded in detail before the next interview is analysed.	**Next Transcript** A new open codes folder is created in NVivo in which to store the new codes created for each participant's transcript separate from other transcripts. Each transcript is therefore treated as a new analysis (i.e. corresponding to IPA Steps 1-4) as far as possible bracketing out references to codes in other transcripts.
Step 6: *Looking for patterns across cases* a meta-analysis of the various themes for all the interviews takes place; highlighting differences and similarities across participant experiences. Recurrence of themes across cases is considered and superordinate themes are identified.	Emergent themes from the participant's transcript are copied into a common 'Themes' folder where they are all merged together for the first time (leaving the category folders for each participant intact). A process of merging and further consolidation of superordinate themes may be conducted within the Themes folder.

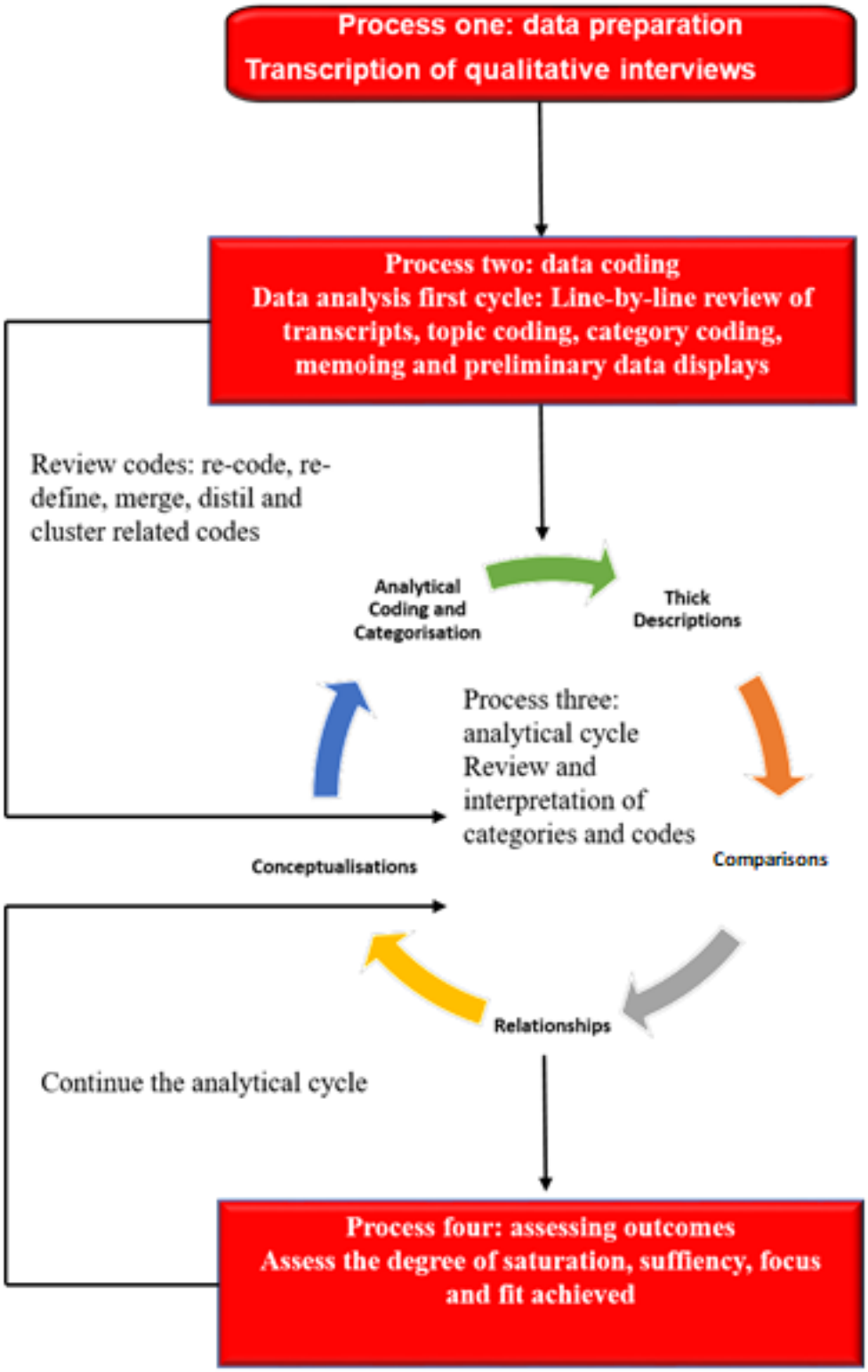

Figure 3.1 Analytical cycle – Adapted from Hennink, Hutter and Bailey, (2011).

CHAPTER 4: FINDINGS

4.1 Chapter Introduction

Following intensive familiarisation with the interview data (transcribing, re-reading, coding, analysing), and interpretative phenomenological analysis (IPA) of the 12 interviews, a number of themes were identified. This findings chapter reports upon the identified, superordinate and subordinate themes, followed by an interpretation of these. Illustrative extracts are used to provide the reader with direct access to the family caregivers' spoken words and an insight into their perceptions and lived experiences. Please note that direct extracts from the transcripts are shown in italics and that the use of three full stops indicates the removal of superfluous text. This was done to aid the clarity of the points being expressed by the respective interviewee, which is intended to maximise the readers' ability to inhabit the caregivers' world. In keeping with IPA's double-hermeneutic, the account provided below includes the researcher's interpretative analyses of caregivers' accounts, which strives to facilitate a deeper understanding of caregivers' lived experiences. This chapter closes with some recommendations based upon caregivers' suggestions and views.

4.2 Overview of the Superordinate Themes

Interpretative work on the 12 interviewees' transcripts revealed two overarching superordinate themes, which represent caregivers' key experiences. A number of subordinate themes were identified within each superordinate theme. These superordinate and subordinate themes are presented in Table 4.1. The first superordinate theme: 'You feel all their pain' — relates to how caregivers were impacted by having their family member suffer with SMI. The second superordinate theme: 'A vital experience of growth and healing through relationship' — concerns caregivers' experiences of engaging in the FFRPS 6-session intervention.

Table 4.1
Summary of Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes	No. participants who evidenced subordinate theme
You feel all their pain	➢ **The trauma of being rendered powerless**	**10**
	➢ **Shame and fear: It's too close to the bone**	**12**
	➢ **A selfish and impossible illness**	**10**
A vital experience of growth and healing through relationship	➢ **Having someone walk in my shoes**	**11**
	➢ **Realising I'm not alone**	**12**
	➢ **Feeling heard and held**	**11**
	➢ **Finding my strength**	**10**
	➢ **A liberating shift from fear to trust**	**9**

4.3 Superordinate Theme 1: You feel all their pain

Interviewees spoke about the trauma they experienced due to having a family member with a mental illness. Their trauma was experienced as an attack at many different levels. A common thread throughout people's narratives related to how this experience exceeded their perceived ability to meet its demands and disrupted their frame of reference and sense of safety.

4.3.1 The Trauma of Being Rendered Powerless

Caregivers expressed how terrified and debilitated they felt by the experience of having their family member develop mental illness:

> *"It's something I'd never saw before, you know, you don't know where to start, you don't know who to ask, you don't know where to go, and of course if you were in a normal, an ordinary sort of situation, you'd have the capacity to think 'maybe if I go down that avenue' but when you're in that desperate situation, you are so bogged down by it."{Leah}*

> *"It's only when it, it comes to your own door and it hits you like a truck, a big truck coming down the road." {Claire}*

Leah conveys how the trauma of witnessing her loved one experience SMI disrupted her frame of reference, overwhelmed her, and impeded her ability to think, and cope, rationally. Claire's use of the phrase "own door" and the violent image of being hit by a "big truck" captures how intensely personal, and crushing, this experience was. As is the nature of trauma, the pain and complexity of each interviewee's experience was unique but common themes of fear, and a perceived inability to cope, permeated caregiver's narratives:

> *"I remember one night, I used to get, for years, I'd get a text message saying 'I don't want to be in this world anymore'... and I'd be climbing the walls with worry she wouldn't come home…I remember her father and myself walking the streets of [name of city] down by the bridges…looking for her. And I nearly went mad to be quite honest." {Alice}*

The above extract illustrates how disturbed Alice was by this and the terror she experienced. Alice evocatively conveys how anxious and helpless she felt, which compounded her sense of trauma. This sentiment was echoed by the majority of caregivers who shared how intolerably helpless, and disempowered, they were rendered by having their family member develop SMI. Natalie's perceptive comment captures much of this. In her frank and unsparing account, she reveals how traumatic this was for her:

"I try to fix things and this is something you can't fix, and that was very difficult…it's an awful feeling, it's soul destroying to be honest, you love somebody and you can't really help them, only support them. I found it very (long pause) God it's soul destroying…it's a very powerless and helpless [position]. One of the hardest things I've ever had to face, when it's been my child, my grown up child that got ill." *{Natalie}*

Here, we gain insight into how for Natalie, who both knows herself to be, and impresses as, a very capable lady, this experience of being rendered powerless was unbearable, and perhaps disrupted her sense of self. Natalie's heavy, significant pause felt as though she was allowing herself to revisit this helpless place, beyond the rational brain, in order to try to find words to convey her profound experience of it. Natalie communicates how devastating it was for her to have to accept that she could not prevent, or lessen, her child's suffering.

A number of interviewees spoke about the trauma of having their family member hospitalised:

"Nothing prepared me for that challenge of my son being in a psychiatric ward (voice trembling). I saw some very, very sad cases there and he was as bad as any of them. It's so tragic and nothing prepares you for it (significant pause) nothing prepares you for it. It goes to the depths of your being. It does, it goes to the depths of your soul.' {Edie}

"[name of doctor] said 'I think we'll be keeping you today' and I kind of had myself told that going out in the car but still… it was like someone punched me in the gut, it was really hard…she said 'well you can stay of your own will or we will restrain you'. Just to see him walking away from you… Jesus Christ like, how did we get here?" (whispers) {Sarah}

As powerfully conveyed by the above quotes, the experience of having a family member hospitalised due to SMI, was traumatic. This was captured by Sarah's and Edie's striking use of language and Edie's haunting repetition of the phrase "nothing prepares you for it". Caregivers' frequent use of spiritual language (e.g. soul, God, Jesus Christ) perhaps suggests that the experience of being powerless in the face of their family member's mental illness, shattered their sense of safety, and the illusion of control, prompting an existential or spiritual crisis. Sarah's utterance "how

did we get here?" betrays how intimately she is connected to, and impacted by, her son's SMI. Similarly, Natalie incisively identifies how inextricably linked one is to one's family members:

> *"At the end of the day, if a family member goes down, it's a shared experience because it affects you. You can't turn that emotion off, you feel all their pain, they might be the one experiencing it, but you feel it."{Natalie}*

Natalie shares her experience of feeling "all" of her family member's pain, and her perception regarding how the suffering of a family member is "a shared experience". Interestingly, some caregivers elaborated further by articulating how they and their family members, who have mental illnesses, experienced emotional contagion:

> *"There is the mental illness and the psychological trauma [of having a family member experience SMI] and sometimes the two are very similar in the day to day reality of things." {Julia}*

As illustrated by Julia and Natalie, caregivers reported how deeply impacted they were by their family member's mental illness. There was a strong sense of dissonance between caregivers' past and present relationships and roles. By referring to "the day to day reality of things", Julia conveys how, effectively, she was also incapacitated by her family member's SMI. In addition, the secondary and possibly invisible nature of her suffering may have made it all the more confusing, and difficult to accept.

This subordinate theme captures how frightening, chaotic and disruptive the experience of having a family member suffer with SMI was for interviewees, and how it overwhelmed their perceived ability to meet its demands. A desire to be able to save or protect their loved ones, and for circumstances to be other than they are, is contrasted with the pervasive experience of being rendered powerless.

4.3.2 Shame and fear: It's too close to the bone

Interviewees revealed their fear of SMI and feelings of shame in relation to SMI. Interviewees shared their beliefs about the stigma that surrounds mental illness:

"There is a total stigma around mental health." {Karen}

"There's that stigma with mental health, everybody keeps to themselves and their problem private, you don't talk about it and you don't mix and it's not like another hospital where you talk to the person next to you, or you speak to their visitors or anything like that, it's not in a mental situation, you just don't. Everyone is there like 'oh my God, we don't even want to be here'." {Alison}

Alison provides further insight into the pain of the experience of SMI. The associated shame, and one's struggle to accept it, unwittingly perpetuates the stigma that surrounds SMI. Alison's use of collective pronouns (e.g. "everybody", "you", "we") and censorial comments (e.g. "you don't talk about it") perhaps reflects how she has internalised societal attitudes towards SMI. Based upon caregivers' narratives, it would seem as though the stigma that surrounds SMI is perhaps a major contributing factor to feelings of isolation. Each caregiver, at some point during the interview, expressed how isolated she felt by the experience of having an SMI family member:

"I felt so alone, I did now, I felt frightened, I felt the whole range of emotions. I actually thought I was the only one going through it." {Alice}

"It's been terrible. I've lost weight, I couldn't eat, I couldn't sleep. I thought my head would explode. I felt (significant pause) that I was on my own." {Sarah}

Feeling isolated was prevalent across caregiver interviews and seemed to be a particularly painful aspect of the experience, which may be attributable to the shame and stigma that surrounds SMI. Some caregivers referred to the stigma that individuals with SMI can experience within the community:

"If you have somebody coming there to the flat here, or to no.1 there, with a mental illness…they are being looked at like 'sure they are not right, he is a freak' like. I will say of my own son, if I saw him walking down the road and I didn't know who he was, I'd say 'God help that poor young fella, he's not right at all.'"{Edie}

Above, Edie defiantly admits her own internalised stigma towards others who seem different. Edie, unflinchingly, proceeded to confess her own struggle with self-stigma in relation to mental illness:

"The challenge really, the big, big challenge within mental illness is the actual acceptance that this is in your own family. And I've lived that." {Edie}

When attempting to make sense of how society as a whole, and they themselves in turn, respond to SMI, some caregivers proposed that the invisibility of SMI makes it more difficult to respond to with compassion:

"You see you can't put a bandage on the brain…if she was in hospital I'd have to look after her, if she was having an operation to fix a broken hand or leg, I'd be looking after her. It's just because people can't see it." {Alice}

"If I had like say, my son seriously physically ill, you'd be talking to him, you'd be stroking him, you'd be nurturing him. But you stop that when it's mental." {Edie}

Edie's inconsistent use of pronouns here perhaps reflects both a need to distance herself somewhat, from her searingly honest admission, and, furthermore, is an example of how she has assimilated and internalised societal attitudes towards SMI.

In addition to their sense of stigma and shame, interviewees shared their fear of SMI, especially due to the well-established genetic, and intergenerational, predisposing factors to SMI:

"It was my worst nightmare for it to happen…" {Natalie}

"Then you have the fear because she [mother] has a mental illness, would I ever have a mental illness?...Then you have the fear for your children and your grandchildren. It's always a fear."{Alison}

Realising that you yourself, and your loved ones, are predisposed to SMI is a heavy burden to bear. Caregivers expressed how painfully raw the subject of SMI can be due to how intolerably vulnerable and powerless they feel in the face of it:

"I don't understand it (SMI) so maybe I need to learn a bit more about it but l am frightened by it, I am. It's too close to the bone. It's very close to the bone and I am frightened by it." {Natalie}

"I get depressed when I come out of there [psychiatric hospital]. I don't like going out there. When you see people going around and you feel (long pause). When you come out you say 'God, there for the grace of God go I.'" {Mary}

Above, Natalie suggests that her lack of understanding of SMI may contribute towards her feelings of vulnerability in relation to it, but then she acknowledges that her fear of SMI stems from her personal experience of it (both her mother and daughter have suffered with SMI), and possibly her fear of herself and/or other family members developing it. Similarly, as Mary spoke, her visceral dislike of psychiatric hospitals was palpable and she admits how sad and perturbingly vulnerable they can make her feel.

This subordinate theme shed light on family caregivers' fear of SMI, and feelings of shame in relation to SMI. Analyses revealed how caregivers' feelings of shame, and struggles to accept that it had occurred in their families, unwittingly perpetuates the stigma that surrounds SMI. The stigma that surrounds SMI seems to be a major contributing factor to feelings of isolation, which each caregiver expressed.

4.3.3 A selfish and impossible illness

Each participant identified how their family member having an SMI, caused a strain within their relationships and evoked a maelstrom of conflicting feelings within them. For instance, Natalie provides insight into how challenging it was, to be around her unwell daughter:

"She was very hard to be around. I love her but other people wouldn't be suffering it." {Natalie}

Natalie's comment, and the forcefulness with which she said it, revealed that she experienced ambivalent feelings towards her daughter. Interestingly, many caregivers referred to the "selfish" nature of mental illness:

"I think depression is a very selfish illness, I do because she just thinks of nobody but herself, I'm not saying that in a bad way but she is just so taken up with what is going on in herself that she's not able to think about anything else." {Alice}

Alice retains compassion for her daughter while describing how she perceives her to be self-absorbed, and lacking consideration for others, due to her SMI. Externalising the SMI as "selfish" may serve as a useful vehicle to make sense of, or cope with, ambivalent feelings towards one's SMI family member. Others struggled to discern what behaviour was due to SMI, and what was simply being selfish:

"We can all be selfish, it's a trait we all have but I think in particular my family member can be very selfish and I don't think it's all down to mental health sometimes…. We get frustrated, well I get very frustrated." {Natalie}

Natalie shares how frustrating it can be to live with someone experiencing SMI. Some caregivers seemed to struggle with guilt when alluding to their ambivalent feelings towards their SMI family member:

"The nurses say it's the parents they feel sorry for like because they have to go about their business and keep the show on the road. It's harder on them because the person that's unwell, they're only thinking solely of themselves like. She'd [daughter] never you know (trails off), I suppose it was all thinking of herself like you know" {Martha}

In the above example, the nurses expressing their views seem to provide Martha with the permission to express what she herself felt. Even with that, she paused and faltered before being able to disclose "I suppose it was all thinking of herself". Here, we gain insight into the complexity, and strain, of ambivalent feelings.

Other interviewees were more confident in being able to assert how the care and support they provided to their family member, had become taken for granted:

"They don't expect you to need any time for yourself. They expect a lot all the time and I'm getting older now like and I don't have a lot to give all the time and sometimes, I just don't want to." {Alison}

Alison shares how she constantly feels taken for granted, which has taken its toll and has led to feelings of resentment. Similarly, others expressed their feelings of anger, in relation to their SMI family member, in a forthright manner:

"Then I would get angry, you know 'cause there is only so much like, the first couple of times I wouldn't but then after a while you just go 'to hell with it!, why am I putting up with this shit?'" {Sarah}

Sarah conveys how the ongoing strain of living with her SMI family member has worn her down and has caused her to lose her temper. Experiences of extreme frustration followed closely by guilt or remorse were common across participant narratives. Caregivers struggled with a multitude of conflicting and distressing feelings including frustration, anger, guilt and confusion. Leah captures much of this:

"You know just the aggression with her and the violence and then she goes from being aggressive and violent, she's physically hit me and things like that…to being, within two minutes, this sweet little, you know 'I love you mum. Are you OK?', and it's on an emotional level, I can't deal with it. It's impossible."{Leah}

We gain insight into how dysfunctional Leah's relationship with her daughter can be, and into the unpredictability, and abuse, Leah experiences within it. Caregivers described how their family members' SMI had a traumatic impact upon the rest of the family:

"Celine's mental health has affected everybody in the family, it has kind of really shook us so it has (significant pause) it's made us fragile."{Natalie}

"When my husband is ill, it affects all of us. It has been very stressful for the children as well seeing their dad unwell… I talk to my son he's 11 (tears), it's really hard when he calls his dad mad, you know it's hard."{Julia}

Natalie's arresting use of the words "shook" and "fragile" conveys how deeply distressing the experience has been. The sense of how it has disrupted the whole family's frame of reference, and sense of safety, was palpable. Not only were interviewees suffering due to witnessing the pernicious impact of SMI, as it took hold of their family member, they also acutely felt the pain of the other surrounding family members:

"Physically, mentally, the whole family is affected you know, my husband is hardly able to cope with it as well... I mean he's got to the point now where he actually says to me "I can't handle her. I can't handle Rita anymore"…I hate seeing him like that. It breaks my heart."{Leah}

Leah shares how witnessing the destructive impact SMI has had upon the rest of her family, has been devastating.

As can be seen from the above quotes, in the aftermath of a loved one becoming mentally unwell, each family has grappled with its own unique challenges. One participant described how her son has become very protective towards her and resentful of his sister who has SMI:

"My son is always saying…you have to look after yourself, he's afraid of his life in case I die and if I do die, he'll blame her, I know he will, so the whole family is [impacted] (tears)" {Claire}

This subordinate theme illustrates the complexity of how SMI impacts the whole family, and causes strain both intrapsychically and interpersonally. In the aftermath of a loved one developing SMI, each family grappled with its own unique challenges. However, experiences of extreme frustration followed closely by guilt or remorse were common across interviewees' narratives. Analyses revealed caregivers' discomfiture with experiencing ambivalent feelings towards their unwell family members.

4.4 Superordinate Theme 2: A vital experience of growth and healing through relationship

This superordinate theme examines caregivers' experiences of engaging in FRIENDS Family Recovery Peer Support (FFRPS), and traces how doing so, led to post-traumatic growth and family recovery. Firstly, how FFRPS benefitted caregivers and paved the way for family recovery is discussed. Next, we examine how the relationship with their FFRPS provider was healing and inspired hope. We then explore how receiving FFRPS led to improved self-care and a strengthening of the self. The final theme considers how caregivers' increased objectivity, and acceptance, led to improved relationships.

4.4.1 Having someone walk in my shoes

All 12 family caregivers stated that they considered receiving FFRPS to have been a very beneficial experience:

> *"It's just, it's invaluable, it's the best thing I could have done was to go and see her [FFRPS provider], seriously, it's vital. It is vital." {Leah}*

> *"It [FFRPS] was excellent; I really found it very helpful." {Natalie}*

Repetition of word "vital" and "really" convey how emphatic interviewees were about how helpful they found FFRPS and how much it meant to them. "Vital" connotes just how critical FFRPS was for Leah, and more specifically, how crucial her own journey of recovery was.

A few caregivers described the benefits they experienced after just the first session. Alice's comment captures much of this:

> *"When I came out I said 'thank God' and ...I said to my husband 'you know what, it's only my first visit but I'm after learning a lot up there!' I actually had a smile on my face for the first time in I don't know how long." {Alice}*

After her first FFRPS session, Alice poignantly describes the relief she felt, and the resultant capacity for her to feel joy once again. Alice's vibrant declaration "I'm after learning a lot up there!"

connotes how empowered she felt. The FFRPS provider's unique ability to relate was frequently identified as important:

> *"…someone who has been through it, they can really relate, you have to walk in my shoes like." {Martha}*

Martha's use of the metaphor "you have to walk in my shoes like" conveys just how necessary it is, in order for healing to occur, for the listener to be able to fully inhabit her experience and to hold a respectful appreciation of how difficult and complex it was.

Interviewees attributed the depth of the connection they formed with their FFRPS provider, to the fact that they shared similar experiences, and felt that the FFRPS provider was able to identify without judgement:

> *"We were able to identify with one another…she understood because she had been there." {Alice}*

Such examples suggest that caregivers experienced a level of comfort, and reassurance, in knowing that the FFRPS providers had SMI within their own families.

However, three caregivers expressed that, in some respects, they had received FFRPS too late and wished that they had received support sooner:

> *"My daughter has had bipolar since she was 16…I imagine if it [receiving FFRPS] had been 15 years ago, it'd be huge."{Claire}*

These caregivers described how, whilst they still considered engaging in FFRPS to have been a beneficial experience, they felt disappointed they had not received it earlier, as they believed they would have gained more from it, and that by the time they did receive it, they had already developed ways of coping with their circumstances.

Eleven of the twelve caregivers attended all six sessions of FFRPS. However, Alison, stopped attending after her fourth session. During her interview, Alison expressed the view that, although she regarded the sessions as beneficial, she chose to stop attending because she found that they brought up a lot of troubling feelings:

"What I did find about the meetings was that it brought up an awful lot of feelings from the past that I thought I was well and truly over with. Talking about things when my mother first became ill…it just dug up a whole load of stuff for me that I thought was dead and buried. And I didn't like it! (laughs)…It's a can of worms I don't want to open like. I didn't expect that." {Alison}

Alison recounts how engaging in FFRPS led to her discussing and reflecting upon difficult past experiences. Alison felt unprepared for how doing so, affected her emotionally. Alison had been utilising her own well established coping mechanisms and defences in order to manage her anxiety and difficult feelings in relation to the past. The description of "dead and buried" implies that Alison enlisted the use of suppression and avoidance in dealing with her mother's mental illness. Engaging in FFRPS disrupted and threatened her use of these coping mechanisms. The metaphor of "a can of worms" is evocative of festering entities that have been sealed off.

This subordinate theme identifies how caregivers considered FFRPS to have been a very beneficial experience. Caregivers expressed how helpful it was to meet with someone who could relate and genuinely understand. However, three caregivers expressed that, whilst they still considered FFRPS to have been beneficial, they believed they had received it too late.

4.4.2 Realising I'm not alone

This theme considers the unique benefits of peer support and therapeutic nature of the relationship that caregivers developed with FFRPS providers. All 12 interviewees underscored how important this relationship was. Edie's pithy quote captures much of this:

"She was just so energetic, so positive, so empathic, [and] compassionate and so caring; we actually had a huge connection." {Edie}

The family caregivers proceeded to reflect upon how they benefited from having developed this quality of relationship. Across interviews, there was an overwhelming consensus that receiving FFRPS eased their feelings of isolation:

"The loneliness of it is gone, if I was to take one thing out of it, that is a very important thing, the isolation that you feel (significant pause), so that's gone, thank God." {Alice}

"It alleviates your stress because you know you're not alone. When you leave that session you're lighter after hearing that person's story in your story." {Edie}

As suggested by the above examples, a hugely important aspect of receiving FFRPS, which caregivers frequently identified, is that it helped to normalise the experience of having a family member with SMI. Realising that "you're not alone" seemed to lessen the stigma and feelings of shame that surround SMI, which caregivers reported in the first superordinate theme. Realising, and receiving validation, that their own reactions to SMI and that their complex feelings, including grief and anger, were justified, was healing. Leah captures much of this:

"[it gives you] the feeling that…other people are going through this thing…sometimes ten times worse, sometimes not, but everybody has the same, the reactions that we have (long pause) and that we're healthy and that it's to be expected." {Leah}

Leah's significant pause felt as though she was grasping to find words to articulate what a confusing, lonely and often painful place she had been in. Having those wordless experiences understood by the FFRPS provider, and her reactions validated was an immense relief. Across caregivers' narratives, it was evident that FFRPS provided them with a safe, allowing, and compassionate space to share and process their experiences.

A couple of caregivers who had previously attended personal counselling compared those experiences with FFRPS:

"Compared to any other one-to ones I've had it felt different, more helpful… I really liked it when she said, when I said something, it made her think…. [it was] definitely the best in terms of what I took away from it that's useful and beneficial and applicable." {Caoimhe}

Caoimhe went on to share how FFRPS "felt different" due to there being an enhanced sense of equality and reciprocity within the relationship, which led her to more realisations that were more

helpful and more “applicable". Learning that, by sharing her experiences and views, Caoimhe had inspired the FFRPS provider to reflect, seemed to have boosted her self-confidence and to have made the experience all the more rewarding.

How their relationship with the FFRPS provider inspired hope, was a common thread throughout interviewees’ narratives:

> *“Nothing compares to having somebody who has gone through it themselves. But what also happened is that I felt inspired seeing how that person has been through all of that … and how she was still able to bounce back.” {Karen}*

> *“The FFRPS was a great support to me, I got the hope there ‘cause I was a bit (long pause), I was on the edge now.” {Natalie}*

The above examples illustrate how, the very fact that the person who was providing them with support had survived similar difficulties, instilled a sense of hope, encouragement, and increased resilience in caregivers. Just how much Natalie had been struggling, and the importance of this burgeoning sense of hope, can be inferred from both the content and halting flow of her words. Natalie’s reference to “the edge” is of interest as it felt ominous when she spoke those words, and perhaps suggests that she had feared for her own mental health, or even her survival. Images of a cliff’s edge, or the metaphorical edge between mental illness and health are evoked.

This subordinate theme identified unique benefits of peer support and highlighted how the relationship with the FFRPS provider inspired hope. A hugely important aspect of receiving FFRPS is that it eased feelings of isolation and helped to normalise the experience of having a family member with SMI. Realising that “you’re not alone” seemed to lessen the stigma and feelings of shame that surround SMI.

4.4.3 Feeling heard and held

Analyses revealed that engaging in FFRPS was a therapeutic experience for 11 of the 12 caregivers. Caregivers expressed how healing it was to feel heard, without judgement, and to have their suffering acknowledged and validated:

*"Nobody had ever asked me how **I** felt…All you see, in doctor's surgeries for example, is 'Are you suffering from this? Are you suffering from that?' but there is nothing about 'Are you living with someone who has a mental illness?' {Alice}*

Implicit in Alice's comment is the suggestion that, previously, she felt that both she, and her suffering, were invisible or inconsequential. Similarly, Natalie emphasised the importance of having her own voice heard:

*"I found the one-to-one great because it wasn't about your family member it was actually about **you** and… your voice is being heard." {Natalie}*

Natalie's emphasis on the word "you" perhaps suggests that she also felt invisible or inconsequential relative to her daughter's SMI. Similarly, Leah illuminates which aspects of FFRPS facilitated her recovery journey:

"It's partly through speaking to someone who has been through something similar but it's also somebody recognising how desperate things are for you." {Leah}

The above example illustrates how profoundly healing it was to feel seen, and heard, and to have their suffering recognised, acknowledged and validated. Caregivers reported how much it meant to be asked about themselves and to be treated with respect and consideration.

A number of caregivers referred to how their family member's SMI had led to a loss of their sense of self:

"I was finally able to talk to someone about how I was feeling. Thank you for letting me talk about me. Me. There was no me there for a while, I wasn't there at all, I was in Lynn." {Alice}

"It opened my eyes to that again, because I'd got lost as well. We get lost in it [family member's SMI] like and we don't even realise it." {Edie}

The above examples provide insight into how, when SMI occurs within a family, fusion (i.e. enmeshment), and lack of differentiation and awareness often follows. Caregivers spoke about how the FFRPS allowed them to become aware of, and in touch with, their own feelings once again as opposed to feeling "lost" in their family members' SMI. This combination of feeling heard and understood, within a safe relationship, with somebody who has survived the experience, seemed to have had a healing effect:

"I felt that after each meeting, when I went home, I was a lot calmer." {Karen}

"You have this constant knot in your stomach all that time; you're living 24 hours with a knot in your stomach, that's eased. I won't say it's gone completely but it's eased an awful lot." {Alice}

As suggested by these comments, caregivers found that receiving FFRPS alleviated some of the physical and emotional stress they were carrying. Caregivers commonly spoke in terms of the relief they felt afterwards, and of feeling "lighter" from having been able to express their feelings and share their experiences:

"I go to see her and for the rest of the day I feel sort of lighter." {Leah}

"It got rid of so much anxiety that I didn't even realise I was carrying." {Caoimhe}

Caoimhe provides insight into how she had grown so accustomed to "carrying" anxiety that she was not even aware of the extent of the anxiety she was experiencing.

Karen spoke specifically about the impact of being listened to, by the FFRPS provider with, patience:

"It was the patience that I was given and the listening ear, I found that it decluttered and de-scrambled my mind." {Karen}

Karen lyrically describes how the space and patience she was provided with, enabled her to think more clearly and to process and integrate her experiences. Other caregivers spoke in terms of feeling 'held' or contained by receiving FFRPS:

> *"Rita had an absolute horrendous anxiety attack, meltdown…you don't know how to cope with something so random and so out of the blue and the one thing that kept me grounded was knowing that in a week's time and I can talk to [name of FFRPS provider] about it…if that happened and I'd have had nobody to tell about it, [it] would have been totally different." {Leah}*

Above, Leah captures the comfort and assurance she experienced in knowing that she could talk about this "meltdown" with the FFRPS provider, and conveys how, even just knowing this, helped her to stay grounded and to be more resilient. Having this regular support, provided Leah with a steadier footing to weather these storms, which was vastly different from having "nobody" to discuss them with.

This subordinate theme illustrates the therapeutic nature of the relationship that interviewees developed with FFRPS providers. Caregivers expressed how healing it was to feel heard, without judgement, and to have their suffering acknowledged and validated. This combination of feeling heard, held and understood within a safe relationship, with somebody who has survived the experience, seemed to have had a healing effect.

4.4.4 Finding my strength

This theme traces how receiving FFRPS, led caregivers to appreciate the importance of practising self-care, which gradually led to increased resilience. Caregivers expressed how, previously, they were too consumed by their family member's SMI to even think about self-care:

> *"I never even knew it (self-care) was important, I thought it was just my husband, my husband, my husband all the time, I had no idea but I know now! (laughs)." {Julia}*

> *"You see I was thinking so much of Lynn, I actually put down on the form that Lynn's recovery would be my recovery, I was so wrong!...I was leaving myself go, to concentrate on her, I know now that I have to look after myself." {Alice}*

Julia's repetition of "my husband, my husband, my husband" and Alice's reference to how her daughter's recovery "would be my recovery" provide insight into how undifferentiated they were from their SMI family members and how they needed to learn to healthily separate.

Interviewees elaborated upon how, by receiving FFRPS, they had learned that practising self-care actually improved their relationships with others, and their quality of life. This is perhaps best illustrated by Julia below:

> *"I found that when I'm well, the rest of the family tends to be well…Recognising my own needs and acknowledging them at this stage of my life is really important to me, to make me feel that I can have a good life in the next 20 years or so without being entirely burnt out, thinking 'that's my lot' you know?. Now, I think that we can have a normal life and work towards goals that other families have where there is no mental illness." {Julia}*

Julia's realisation that when she is well, "the rest of the family tend to be well" seemed to provide her with the permission, or justification, to look after herself better. In order to sustain her caregiving role, Julia reported that she has come to appreciate the need for her to practise regular self-care in order to prevent her from becoming "entirely burnt out". Since beginning her recovery journey with FFRPS, Julia now believes that her family can have "a normal life", which is not dominated, or dictated, by SMI. Julia explains that she has come to realise that it is not only her husband who is recovering from SMI, but that she, and the rest of her family, are also recovering from the shared traumatic experience:

> *"I'd never understood the recovery piece before, I never conceived that there was family recovery as well as patient recovery and going through this process with the FRIENDS initiative [FFRPS] has allowed me to see that and I'm delighted to see that as well…so that's where I think the FRIENDS initiative can be so powerful." {Julia}*

One caregiver, however, described the challenges she experienced in relation to the FFRPS provider's suggestion of practising self-care:

"It was kinda about making time for yourself and I don't come from that era, do you know what I mean? We were brought up to just get on with it like… it was a totally new concept for me." {Alison}

Alison conveyed how uncomfortably foreign this concept of self-care was for her. Alison explains how this concept seemed to clash with the values, by which she was raised, and loyally adhered to. When asked about what it was like for her to be encouraged to practise self-care, Alison explained that while, intellectually, she recognised the merit of it; it was too far removed from her "role in life", how she had been socialised, and, perhaps, her sense of identity:

"The more you think about it, the more it makes sense to try and look after yourself while you're looking after somebody else, but that's never been my role in life, I'm always looking after someone else." {Alison}

Following over three decades of supporting her SMI mother, the caregiver "role" seemed to have been the only role that Alison was familiar with. Understandably, Alison seemed to experience extreme frustration due to her perceived 'stuckness' in this role; her words were imbued with resentment. Alison elaborated upon how stressful it was to try to change long established patterns of behaviour and other's expectations of her:

"I know I have to make time for myself but I find…you have to fight for your time back you know? You end up having to argue or fight… because you're always expected to be, you're always expected to do, to be, you know, to get, to, fro." {Alison}

While she recognised her need to make time for herself, Alison seemed frustrated that attempting to do so only resulted in additional stress for her. The verb 'fight' was used a number of times, which conveyed how acrimonious this process of attempting change, to allow self-care, was. This difficulty that Alison experienced lends support to the argument that it is more effective to receive FFRPS shortly after one's family member has been diagnosed with SMI, before patterns of interaction, and expectations, are established.

Apart from Alison, the other 11 caregivers reported that, as a result of engaging in FFRPS, they felt they had grown in strength and self-confidence, and largely attributed this to improved self-

care and the support they received from FFRPS. Caregivers described how they have learned to take the ups and downs associated with their family member's SMI less personally:

> *"I've learnt to say what happens, happens. That's her episode, her little episode. I was really over sensitive at the start; now I feel, I won't say stronger, but I will say I feel like I've nurtured myself better." {Karen}*

Karen elucidates how by better nurturing herself, she has become more differentiated from, and resilient to, her partner's "episodes" and has become more resilient in terms of not allowing it to determine how she feels about herself. Caregivers described how they feel as though they have grown in strength:

> *"I have grown stronger in myself…after the 6 weeks…I didn't realise how weak I was until I started doing the FFRPS, to be quite honest." {Alice}*

> *"Before I went to see her [FFRPS provider] I felt like a victim. Now I don't. I feel like I'm someone who is dealing with someone who is ill…it just gives you the ability to find your strength." {Leah}*

The above examples illustrate how caregivers experienced an increase in their confidence, and resilience, due to receiving FFRPS. Alice's reference to "weak" and Leah's to feeling like a "victim", suggest that they had been feeling helpless, and possibly even persecuted, whereas now they both view their circumstances with greater clarity, and feel more empowered. Edie further elucidates this process of growing in strength and self-confidence, as a result of engaging in FFRPS:

> *"You become a recluse yourself within it [son's SMI], you become very isolated and it's chipping away at your self-confidence. What the sessions did for me was restore my confidence, it gave me passion again." {Edie}*

Edie shares how she had gradually felt worn down, and isolated, by her son's SMI, but that FFRPS provided her with a renewed sense of vigour. Edie's inconsistent use of pronouns perhaps reflects her absence from her own experience of becoming a "recluse" within her son's SMI, which

contrasts with how fully herself and enlivened, she felt, as a result of FFRPS. Other caregivers identified how engaging in FFRPS enhanced their ability to cope with challenging circumstances:

> *"Before I just locked myself away praying that it would be alright…Now I'm able to talk to her about it, you know and say like she said 'I'm going down to the river' and I will say 'and what are you planning to do?'. Before I'd just say 'please Lynn don't, don't please don't go down' but I'm able to, to bear it a little bit more now. Before I'd run in a panic." {Alice}*

A progression from being overwhelmed and threatened, to safety and containment, is evident in Alice's words. Alice's ability to confront and process her own fears, within the FFRPS relationship, bolstered her capacity to bear witness to her daughter's intense fears and overwhelming emotions. Similarly, other caregivers noted how they were now responding to their SMI family member in more conscious, and less reactive ways. This is well illustrated by Leah:

> *"I totally pull myself away from her [SMI daughter] and I couldn't…I didn't know how to do it before I'd met [name of FFRPS provider] and talked things through with her…I can deal with it in a completely different way and I can stay calm and I'm more firm." {Leah}*

Leah alludes to how, as a result of FFRPS, she has become more differentiated from her daughter, which has allowed her to remain grounded and in control. As the above examples suggest, a strong, frequently identified theme across caregivers' narratives, was that of feeling empowered from having received FFRPS:

> *"I felt empowered leaving each session." {Karen}*

> *"The friends initiative [FFRPS] can bail somebody out or help them to bail themselves out I should say!...it can prevent a family catastrophe." {Julia}*

Julia implies how, not only did FFRPS "bail" her out; it equipped her with the skills, and self-confidence, to do so for herself. We gain insight into just how imperative this was for her family when she describes how FFRPS can "prevent a family catastrophe".

Caregivers described how receiving FFRPS supported them in establishing healthy boundaries with their SMI family members, which led to a lessening of dysfunctional dynamics:

""I used to come back from meetings and I'd say…I'll help her but I'm not being a punch bag anymore…I said 'Rita I'm not getting involved in these anymore'. I said 'they're not doing you any good; they're not doing me any good'… She knows there are boundaries now, she hasn't said it, I haven't asked her, but I get the impression."{Leah}

This subordinate theme identifies how receiving FFRPS, led caregivers to recognise the importance of practising self-care, which gradually led to increased resilience and a strengthening of the self. A journey of a growth in strength, understanding, compassion and clarity was tangible and prevalent across interviews.

4.4.5 A liberating shift from fear to trust

Caregivers explained how FFRPS assisted them in gaining a better understanding of, and greater objectivity in relation to their circumstances:

"I'd recommend it [FFRPS] even for a better understanding of what's going on." {Alison}

"It pulls you right back out of it and in that sense it's just, it's the most important, it should be completely side-by-side with all the other mental health team's help." {Leah}

Leah considers it to be so crucial, that she recommends FFRPS should be rolled out to become a central part of the support offered by mental health teams. Some interviewees elaborated on how engaging in FFRPS enabled them to see and think about things differently:

"In the space of those few hours I was out of the house, my attitude changed completely." {Edie}

Caregivers described how this shift in their attitudes, and renewed sense of perspective, was very helpful to them. Julia elucidates how FFRPS prompted her to take the time to consider issues, and avenues, that she had previously dismissed:

"There would be questions asked of me and where I've taken the answers for granted before, I've now stopped and I'm thinking about things differently." {Julia}

Some caregivers described how this increased objectivity and self-confidence, which they gained from engaging in FFRPS, enabled them to better understand how they were, or were not, contributing to problematic dynamics:

"Up until that point you don't know whether what you're doing is [a] help, [or a] hindrance. You don't know whether you're starting stuff. You don't know whether you're antagonising her."{Leah}

Above, Leah describes how, before she began FFRPS, she was feeling overwhelmed by uncertainty and anxiety about how she was responding to her SMI daughter. Similarly, caregivers identified how receiving FFRPS improved their self-awareness in relation to their role in problematic relationship dynamics:

"It made me realise that when I didn't communicate, it came out in annoyed ways that isn't fair on anyone." {Caoimhe}

Caoimhe admirably acknowledges how she became aware of the consequences of her behaviour, and of how her unacknowledged emotions 'leaked' out in destructive ways, when she withdrew communication. Some caregivers became aware of how feeling unappreciated can breed feelings of resentment, and if these feelings remain unacknowledged they can go 'underground' and be, inadvertently, taken out upon the SMI family member:

"If you try to help so much, and then the other party doesn't recognise it, you can feel bad or upset and then can take it out on the other person." {Caomhie}

Caoimhe demonstrates an impressive capacity to honestly examine this challenging relationship dynamic, while holding compassion for both parties. Similarly, Alice provides insight into the difficult realisations that she came to:

"I was probably putting too much pressure on her to be quite honest, not knowing what to do, but I've learned to back off. {Alice}

Alice traces how her own unmetabolised fear, due to "not knowing what to do", remained within the family system and was mirrored within her relationship with her daughter, and was unconsciously played out by her adding "too much pressure". Edie provides us with insight into her journey of increasing self-awareness:

"What I discovered in the 6 sessions is that, you know, I needed to respond with more kindness to him in a way as well…I suppose I became kinder to him out of it...and I 'm not unkind but I had kind of gone silent…It was the kindness of [name of FFRPS provider], and the caring and the love she showed towards me, I was able to give it back."{Edie}

Edie courageously identifies how, in order to cope with feeling intolerably powerless in the ongoing face of her son's SMI, she withdrew and became "silent". However, by receiving FFRPS, Edie experientially came to know, and appreciate, the value of simply being kind, present and available to another human being. Not only did this experience of receiving care from the FFRPS provider, reinvigorate Edie personally, it enabled her to realise how she could be of greater help to her son "I was able to give it back."

Caregivers described how, as a result of engaging in FFRPS, they developed greater insight into how they were, unwittingly, fostering dependency in their SMI family member. Alice captures much of this:

"I was doing too much for my daughter and I've learned how to step back, it was only baby steps because I couldn't just cut straight away…so gradually I stepped back from that so now she's taking her own medication." {Alice}

Alice's choice of metaphor is of interest; her use of the terms "baby steps" and "cut" evoke images of an umbilical cord and weaning a child. They are also suggestive of the fusion, and lack of differentiation, which Alice identified having experienced within the relationship. This may have

made it more frightening for Alice to step back. By Alice becoming more differentiated and empowered, so too has her SMI daughter "she's taking her own medication".

Similarly, Natalie provides examples of the realisations that she has come to, due to the enhanced objectivity she gained from FFRPS:

> *"Her journey is her journey. I wasn't able to help her only gain tools for myself so two people aren't falling down and making it worse. Rather than being supportive, I have to try and be strong and look after myself so that my daughter can look after herself." {Natalie}*

Here, Natalie explains how she has come to recognise that the most helpful thing that she can do, is to focus on keeping herself well, so that she can model healthy self-care for her daughter.

This increased objectivity, improved coping skills and self-confidence, which caregivers identified as a direct consequence of FFRPS, prompted them to disentangle, and distinguish between how they feel about themselves, as distinct from their loved one's SMI.

Interpretative work on the interviewees' transcripts revealed a sequential and recursive pattern within their recovery journeys. After receiving care within the FFRPS relationship, caregivers were able to process and integrate their own trauma (due to having a family member suffer with SMI). As a result, caregivers grew in strength, they were more 'freed up' to be objective about their role in maintaining dysfunctional dynamics within the family, and were more emotionally available. This sequential journey of recovery, and post-traumatic growth, culminated in caregivers developing the awareness, and confidence, to replace old strategies of providing care with mutually empowering ways of genuinely supporting their family member. While recovery is a gradual, and non-linear, process, much like the ebbing and flowing of a tide, many of the caregivers experienced this sequential pattern within their recovery journeys. A schematic representation of this sequential and recursive pattern within their recovery journeys is presented in Figure 4.1.

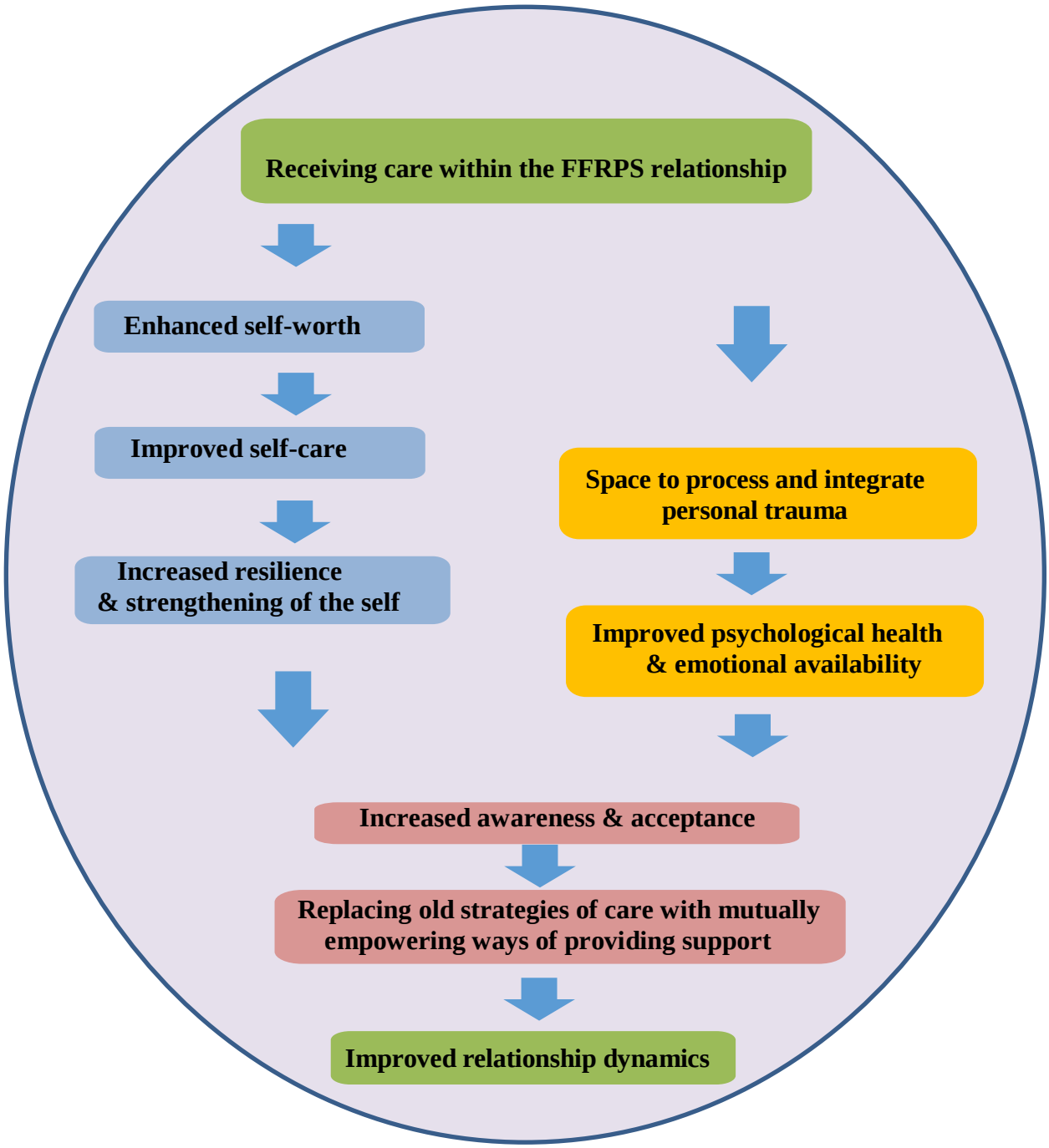

Figure 4.1 How Receiving FFRPS led to Post-traumatic Growth and Family Recovery.

Across interviews, caregivers reflected on how, as a result of engaging in FFRPS, their acceptance of their circumstances, as well as their trust in their ability to cope, had been greatly enhanced. For many caregivers grief and sadness could now coexist with a sense of acceptance:

> *"This is going to be our life and this is Celine's life. It isn't what I wanted for her, it isn't what I'd like for her, I can't change it but we can change our response to things."{Natalie}*

Natalie highlights the central role of acceptance in adapting to a life with SMI. She charts a pragmatic process of adjustment, while choosing to focus on what she does have agency over: "we can change our response to things". Similarly, Caoimhe provides insight into her process of adjusting to a life with SMI and increased acceptance. Caoimhe shares how, previously, she attempted to manage the stress and unpredictability of her mother's mental health by being very "controlling" but that since receiving FFRPS, she has developed a greater capacity to surrender to 'what is':

> *"I've learned so much that never even occurred to me before, such as let go of control…Something that really stood out for me, and don't think I'll ever forget it, is to let me let my mam be my mam." {Caoimhe}*

This ability to surrender control involves relinquishing instinctive, yet misguided, attempts to help, which are motivated by both love and fear. Doing so requires great courage, trust and a capacity to tolerate uncertainty. It is often a counterintuitive lesson, to learn that one needs to step back and 'do' less for a suffering loved one. FFRPS seems to have been very helpful in terms of supporting family members to acquire this wisdom:

> *"[I noticed that] things go in cycles especially because we were meeting on a weekly basis. If I let the bad days and the good days come, it took a lot of the fear out of it so it lessened my feeling that I had to control the illness…All of this has made me trust her more…And now I see her being independent and being well able." {Caoimhe}*

Caoimhe charts how FFRPS led her to trust her SMI mother more, which led her to provide the space for her mother to become more independent and "well able."

Similarly, Alice reflects upon how acceptance, allowing and trust, have been fundamental components in adapting to her daughter's SMI:

> *"I know it's going to happen again but I haven't that intense fear, that intense fear is gone. I'll get through it. She'll get through it." {Alice}*

Alice's words, and the steadfast nature with which she proclaimed them, conveyed the progress she has made, since attending FFRPS, in terms of her ability to cope and surrender to the inevitable. This growth of profound acceptance is perhaps most powerfully captured by Alice when she describes how she has surrendered to the fact that her suicidal daughter is an autonomous being:

> *"How I knew it [FFRPS] worked was when she went out that one night…and I said 'let her be ok' but I'd already made peace with it if she wasn't, [before] I'd never dream of accepting something like that! I'd have gone mad at the world! I said to myself 'I love you Lynn, but if you do, do something, I didn't do it to you.'" {Alice}*

Alice's ability to bear such a disturbing prospect is remarkable. Her last line 'I didn't do it to you' is striking and painfully telling of the torment she had previously experienced due to feelings of guilt and responsibility.

The above extracts highlight how personal acceptance of SMI promoted a sense of liberation for caregivers, who recognised a need to focus more on their own lives. Interestingly, caregivers then reflected on changes they had observed in their relations with their SMI family member. The interview data revealed clear indicators that engaging in FFRPS had led to improved communication:

> *"The more we (Caoimhe and her mother) talked about it (mother's SMI), the less scary it was for everyone, it took away the scary element…Since we've opened up that communication, our relationship has gotten so much stronger." {Caoimhe}*

"What has changed in our family since I've gotten FFRPS is that we are all trying to talk properly, to communicate properly and respect each other's boundaries…." {Natalie}

As suggested by the above extracts, the safe reflective space provided by the FFRPS seemed to have facilitated an increase in caregivers' objectivity and acceptance. This increased objectivity and acceptance reportedly led to reduced reactivity, and in turn improvements in unhealthy relationship dynamics:

"The dynamic is better between us, we're not arguing as much I'm not as frustrated…my husband and I, there's just a much more positive synergy between us, it's like getting to know your partner again."{Julia}.

"We are improving the whole time, I mean there are days where he'll irritate me and I probably irritate him as well but the anger isn't there like it was before." {Sarah}

Julia illuminates how her own journey of recovery and concomitant reduced levels of frustration, have allowed her relate in a very different way to her partner and, effectively, get to "know" him once again. Similarly, Sarah notes how much the family dynamics have improved since engaging in FFRPS. Some caregivers reflected upon why they think these changes occurred within their individual families:

"It's so simple but it's so huge, just that respect for each other; it opened up to appreciating each other more." {Caoimhe}

"Since I've been going to FFRPS, she seems to see me differently, it's like she's seeing me with strength." {Leah}

Both Caoimhe and Leah attribute these positive changes to increased respect within the relationship.

This subordinate theme illustrates how FFRPS facilitated an increase in caregivers' self-awareness, objectivity and acceptance. This enabled caregivers to better understand how they were

contributing to problematic dynamics. This theme identified how caregivers' journey of recovery, and post-traumatic growth, led to improvements in their relationships.

4.5 Recommendations

Following the IPA analysis, work was also done to draw out recommendations that caregivers made during their interviews. This final section outlines the seven recommendations that caregivers made. Typical comments are used to support each recommendation.

1. **Provide more support/ funding for family caregivers of SMI family members**:

   "We need to put some funding into this area 'cause people are slipping through the cracks big time and only for carers a lot of them would be dead and they'd be gone through the cracks, and inside in a home looking out a curtain, buckled with medication." {Claire}

2. **The mental health team should listen more to family caregivers:**

   "…of course he (the doctor) knows what he's doing but he doesn't know my family member the way I know my family member and he could listen a bit more to the family…we're living with our family member 24/7". {Natalie}

3. **The FFRPS booklet (Appendix L) should be issued to all family caregivers:**

   "The booklet was fantastic, literally fantastic, it resonates so much, the different roles [victim, persecutor, and rescuer] you play, you know the different role play behaviours." {Edie}

4. **Tailor support to the family's needs. For example, provide one-to-one support to those whose family member has recently developed an SMI and group support for those who have been family caregivers for longer durations:**

   "If FFRPS was in groups, I don't know if I'd have gone, the way I was feeling, I was angry, I was tired, I was crying all the time." {Natalie - family member became unwell 2 years ago}

"I find the one-to-one is very good but I think the group support…would be better." {Mary - family member became unwell 27 years ago}.

5. **Pair family caregivers, and FFRPS providers, who share similar family situations:**

"So this person [FFRPS provider] has a child with a mental illness and I have a husband with a mental illness, and there were times when I wanted to say 'I'm fed up with my marriage and I'm sorry I took on all of that' but I was so conscious that I…would be saying it to somebody who might think 'oh my God what's down the road for my child in relationship?"{Julia}

6. **Provide follow-up support after the FFRPS intervention:**

"You've nowhere to go after the FFRPS, I found that saddened me 'cause…I'd like to be meeting people and 'what's working for you?', meeting up in a social kind of setting with other family members, networking nearly." {Natalie}

7. **Provide opportunities for family caregivers to train to become FFRPS providers:**

"I was thinking if ever there was a course on providing FFRPS, I'd do it if they started training people up."{Claire}

4.6 Chapter Summary

This chapter reported upon the identified, superordinate and subordinate themes, followed by an interpretation of these. Illustrative extracts were used to provide the reader with direct access to the family caregivers' lived experiences. Two superordinate themes were identified: "You feel all their pain" and "A vital experience of growth and healing through relationship". Findings revealed that having a family member suffer with SMI was a traumatic experience, and one which caused strain within family relationships. Findings shed light on family caregivers' unmet needs for emotional support. All 12 caregivers reported that receiving FFRPS was beneficial. The significance

of genuine understanding in the context of experiential similarity was repeatedly identified as invaluable. Analyses revealed a sequential journey of recovery, and post-traumatic growth, across family caregivers' narratives. After receiving care within the FFRPS relationship, and having processed their own trauma, caregivers grew in strength and became more objective about their role in maintaining dysfunctional dynamics within the family. This led caregivers to replace old strategies of providing care with mutually empowering ways of genuinely supporting their SMI family member. In the following chapter, these findings will be discussed in relation to previous literature.

CHAPTER 5: DISCUSSION

5.1 Chapter Introduction

This chapter discusses the study's primary findings with reference to the extant literature (previously discussed in Chapter 2). The additional contributions of the current study are also highlighted. The strengths and limitations of the current study are then considered, followed by a discussion of the potential implications of this research in terms of clinical practice, education and policy. Suggestions for future research are then offered. This chapter closes with a critical reflection on the overall research process, from the researcher's perspective.

5.2 Summary of Findings

By exploring family caregivers' subjective views, this study has extracted rich and nuanced insights into two main areas:

1) The lived experience of having a family member suffer with SMI and

2) The lived experience of receiving FRIENDS Family Recovery Peer Support (FFRPS).

Twelve in-depth interviews were conducted to gain insight into interviewees lived experiences. While appreciating the complexity and diversity of individual experiences, distinct themes, and a common sequential journey of recovery and post-traumatic growth, were identified across narratives during the analysis process. As outlined in the previous chapter, this study elucidated two main themes:

1) 'You feel all their pain' and

2) 'A vital experience of growth and healing through relationship'.

Family caregivers shared how they, and their whole family, were impacted by having a family member suffer with mental illness. Family caregivers then shared their experiences of how engaging in FFRPS 6-session intervention led to post-traumatic growth and family recovery.

5.3 Findings in the context of existing literature

In this section, the main findings of the present study are discussed in the context of existing literature. For the sake of clarity, subordinate theme headings are used to help navigate through the existing literature, and its application to the current study.

5.3.1 You feel all their pain

Findings from the present study reveal that having a family member suffer with SMI is a traumatic experience for family caregivers, which is consistent with previous research (e.g. Kartlova-O'Doherty et al., 2006). However, the present study's findings provide a nuanced extension of earlier studies. A common thread throughout caregivers' narratives related to how this experience exceeded their perceived ability to meet its demands and disrupted their frame of reference and sense of safety. Findings highlight how family members are connected to, and affect, one another. This in keeping with Family Systems Theory (Bowen, 1978; Nichols & Schwartz, 2001).

5.3.2 The Trauma of Being Rendered Powerless

Caregivers expressed how terrified, and debilitated, they felt by the experience of having their family member develop mental illness. Caregivers explained how the trauma of witnessing their loved one develop SMI, overwhelmed them, and, at times, impeded their ability to think and cope rationally. This finding is consistent with existing research, which has identified that the onset of a mental illness can be a traumatic experience for family members and a time of shock, devastation and uncertainty (Farrell & O'Connor, 2017; Johnson, 2000; Kartlova-O'Doherty et al., 2006). All of the interviewees in the present study are female. It has been found that females tend to provide more personal and instrumental care than males, and are also at greater risk of psychiatric morbidity (Fleischmann & Klupp, 2004; Miller & Cafasso, 1992; Yee & Schulz, 2000).

As is the nature of trauma, the pain and complexity of each interviewee's experience was unique, but common themes of fear, and a perceived inability to cope, permeated caregiver's narratives. In previous studies, family caregivers have reported that they need, but do not get, assistance with managing their SMI family member's symptoms and adequate support for their own anxieties and depressed moods (Drapalski et al., 2008; Hummelinck & Pollock, 2006; Kartlova-O'Doherty et al., 2006; Rose et al., 2004; Sin et al., 2005; Winefield, 1994). which aligns with past

experiences reported by interviewees.

Caregivers in this study also disclosed how intolerably powerless they were rendered by having their family member develop SMI, which compounded their sense of trauma. We gain insight into how unbearable it was for caregivers to accept that they could not prevent, or lessen, their loved one's suffering. This correlates with previous research that has explored family caregivers' need for support to manage their own anxieties, psychological distress and depressed moods associated with a loved one's mental health diagnosis (Bailey & Grenyer, 2013; Drapalski et al., 2008; Kartlova-O'Doherty et al., 2006; Zauszniewski & Bekhet, 2014)

Caregivers' narratives reveal how inextricably linked one is to one's family members, and how therefore, the suffering of one family member, affects the others, in keeping with Family Systems Theory (Bowen, 1978) which states that one person's wellbeing is related to other family members' wellbeing. Interestingly, some caregivers elaborated further by articulating how they and their family members, who have mental illnesses, experienced emotional contagion. Emotional contagion and the transmission of negative mood and depressive symptoms between patients and family caregivers have been well documented (e.g. Knoll et al., 2009; Moser et al., 2013).

Family caregivers reported how deeply impacted, and for some, how effectively incapacitated, they were, by their family member's SMI. This converges with previous studies that have identified how SMI can have implications for the way the family functions as a whole (Pilowsky et al., 2006), and studies which have revealed that family members can suffer multifaceted emotional responses due to the challenging and unpredictable nature of mental illness (Kealey, 2005). Family caregivers also struggled to come to terms with, and reconcile, the dissonance between their past and present relationships and roles, which is consistent with previous findings (Byrne et al., 2011). This study builds on previous research by providing insight into how the secondary and 'invisible' nature of caregivers' suffering, seemed to have made it all the more confusing, isolating and difficult to accept.

Family caregivers expressed how isolated they felt by the experience of having an SMI family member. This theme of 'feeling alone' was prevalent across interviews and seemed to be a particularly painful aspect. Previous research has also identified perceived isolation among family caregivers of relatives with SMI (Lucksted et al., 2008; Rose et al., 2006). Findings from the present study are consistent with previous research, which concluded that when someone is experiencing SMI, family members may be suffering in different but equally serious ways (Farrell & O'Connor, 2017; Marshall et al., 2010).

5.3.3 Shame and fear: It's too close to the bone

In line with previous studies, analyses of family caregivers' narratives revealed many had internalised societal stigmatising attitudes towards SMI, which seemed to have contributed to feelings of shame and profound isolation, which caregivers expressed. It is recognised that family members of people with SMI are subject to stigma ''by association'' (Phelan et al., 1998; Struening et al., 2001) and often internalise this (Zisman-Ilani et al., 2013) and experience guilt and shame (Karnieli-Miller et al., 2013; Ohaeri & Fido, 2001; Shibre et al., 2001).

Family caregivers shared their fear of themselves, or of their children developing SMI due to the well-established genetic, and intergenerational, predisposing factors. Family caregivers also revealed how painfully raw the subject of SMI can be due to their personal experience of it, and due to how intolerably vulnerable and powerless they have felt in the face of it. This finding is consistent with previous studies which have shown that family members experience such fears of SMI (Ewertzon et al., 2012; McCann et al. 2011; Schmid et al., 2009).

Some interviewees directly disclosed their struggles with self-stigma in relation to SMI having affected their own family. This converges with findings that stigma substantially impacts on the family members of those with SMI (Corrigan, 2005; Gatsou et al., 2017; Yin et al., 2014), and that, due to stigma, family caregivers may perceive a greater sense of burden associated with the caregiving process (Phelan et al., 1998). This study also builds on previous research by providing insight into how, the shame of SMI, and family caregivers' struggle to accept that SMI had occurred in their own family, had unwittingly perpetuated the stigma that surrounds SMI (e.g. Grandón et al., 2008; Rose, Mallinson, & Gerson, 2006).

5.3.4 A selfish and impossible illness

Interviewees identified how their family members having SMI, caused a strain within their family relationships and evoked a maelstrom of conflicting feelings. Interviewees struggled with a multitude of distressing feelings including frustration, anger, guilt, grief and confusion. Similarly, previous research has identified how family members experience strain due to an array of distressing emotions including anxiety, frustration, shame, guilt, worry, embarrassment and mourning for the person their SMI relative could have been, or once was (McCann et al. 2009; Sin et al., 2012; Wynaden, 2007; Zauszniewski & Bekhet, 2014). Analyses revealed family caregivers' discomfiture with experiencing these ambivalent feelings towards their unwell family members.

Experiences of extreme frustration followed closely by guilt or remorse were common across interviewees' narratives. Some seemed to struggle with guilt when alluding to their ambivalent feelings. Others expressed feelings of anger, in relation to their SMI family member, in a more forthright manner. This finding converges with previous studies, which have shown that adult children may experience ambivalent feelings towards their parents with SMI (Alpert et al., 2003, Foster, 2010; Gopfert et al., 1996; Rutter & Quinton, 1984).

This study provides insight into how caregivers perceived that the ongoing care and support they had provided to their SMI family members had become taken for granted by those family members. This bred feelings of resentment within caregivers. Many caregivers referred to the "selfish" nature of mental illness. For some, externalising the SMI as "selfish" seemed to serve as a useful vehicle to make sense of, and cope with, their ambivalent feelings. This finding is in line with previous research (Karp & Tanarugsachock, 2000), which reported that SMI can provoke emotions of anger and resentment within family caregivers (Karp & Tanarugsachock, 2000).

Some interviewees reported experiencing unpredictability, and abuse, within their relationships with SMI relatives. This finding is consistent with previous research, which found that people with mental illnesses often treat their caregivers with hostility instead of appreciation (Karp, 2002) and that caregivers may experience violence and victimisation within the caregiving relationship (Kageyama et al., 2015; Onwumere et al., 2018).

Interviewees reported how having a family member suffer with SMI, had been deeply distressing for the entire family. Analyses revealed how this experience seemed to have disrupted the whole family's frame of reference and sense of safety. Similairly, previous studies have shown that those who have experienced trauma, often experience low integrative capacity and a resulting inability to engage in critical thinking and reflective action. This can manifest as constraints in their interpersonal relationships (Siegal, 1999; Steele, Van der Hart & Nijenhuis, 1997).

In the aftermath of a loved one becoming mentally unwell, each family grappled with its own unique challenges. Not only were caregivers suffering due to witnessing the pernicious impact of SMI, as it took hold of their family member, they also acutely felt the pain of the other surrounding family members. Through analyses of participant's narratives, we gain insight into the complexity of how SMI impacts the whole family and causes strain both intrapsychically and interpersonally. This finding is consistent with previous research, in which caregivers of SMI relatives reported a family atmosphere of sustained crises and internal conflicts (Rose et al., 2006).

5.3.5 A vital experience of growth and healing through relationship

Family caregivers reported that they considered receiving FFRPS to have been a very beneficial experience. This finding is consistent with international studies that have focused on peer support for family caregivers of people with other chronic illnesses, e.g. dementia (Charlesworth et al., 2011; Fung & Chien, 2002; Greenwood et al., 2013; Keyes et al., 2016; Wang et al., 2012). This finding also converges with the emerging international body of evidence, which supports the effectiveness of peer support programmes for children of parents with mental illness (Foster et al., 2014; Gatsou et al., 2017; Reupert et al., 2012).

5.3.6 Having someone walk in my shoes

Caregivers expressed how helpful it was to meet with someone who could relate. The significance of genuine understanding in the context of experiential similarity was repeatedly identified as invaluable. This finding is consistent with studies which have shown that family members of an SMI relative experienced tremendous relief from having the opportunity to talk with others who could personally relate (Lucksted et al., 2008; Shor & Birnbaum, 2012). This finding also provides additional support for previous research, which indicates that reciprocity of experience is what makes peer support unique and so valuable (Greenwood et al., 2013; Mead & Macneil, 2006).

However, it is important to note that three family caregivers, who had each been supporting their SMI relative for over 15 years, expressed that, in some respects, they felt they had received FFRPS too late. These caregivers described how, whilst they still considered engaging in FFRPS to have been a beneficial experience, they felt disappointed they had not received it earlier, as they believed they would have gained more from it, and that by the time they did receive it, they had already developed ways of coping with their circumstances. This finding lends support to the argument that the needs and preferences of caregivers for SMI relatives are diverse and change over time (e.g. Hatfield & Lefley, 2000; Linszen et al., 1996; Nugter et al., 1997; Solomon et al., 1996), and that a more tailored approach is required to meet the families' needs (Drapalski et al., 2008; Jewel & Smith, 2007). It also lends support to the argument that SMI family members should receive early intervention before negative coping strategies and cycles start developing.

Eleven of the twelve caregivers attended all six sessions of FFRPS. However, one interviewee, who had been supporting her SMI mother for over three decades, stopped attending after her fourth

session and explained that, although she regarded the sessions as beneficial, she chose to stop attending because she found that they 'brought up' a lot of troubling feelings. A more in-depth analysis revealed how engaging in FFRPS disrupted and threatened her use of her own well established coping mechanisms and defences.

5.3.7 Realising I'm not alone

A hugely important aspect of receiving FFRPS is that it eased feelings of isolation and helped to normalise the experience of having a family member with SMI, which is consistent with existing research (Lucksted et al., 2008; Shor & Birnbaum, 2012). The present study adds to earlier research by providing insight into how the realisation that "you're not alone" seems to lessen the stigma and feelings of shame that surround SMI.

Interviewees also reported how therapeutic it was to receive validation, that their own reactions to SMI, and their complex feelings of grief and anger, were justified. This aligns with findings on the benefits of peer support, for family caregivers of relatives with dementia, which include realising that their responses to their situation were 'normal' (Greenwood et al., 2013; Keyes et al., 2016).

In attempting to hypothesise about what made FFRPS therapeutic, one might conclude that it is possible that FFRPS, which is Person-Centred (Rogers, 1951) in its approach, provided the family caregivers with a safe 'space' to begin to process and integrate their experience of having a family member suffer with SMI. Rogers (1951) postulated that if therapists communicated the attitudes of congruence, unconditional positive regard and accurate empathetic understanding, clients will have the necessary freedom to explore areas of their lives that are either denied or distorted and can become self-directing in profoundly wise ways (Rogers, 1951). At times, family caregivers seemed to struggle to find words to articulate what were confusing, lonely and often painful experiences. For this reason, having those wordless experiences understood, and their reactions validated was an immense relief for them. To be fully present and fully human with another person has been viewed as healing in and of itself (Shepherd et al., 1972). FFRPS provided a safe, allowing, and compassionate space for these caregivers.

Another common thread throughout caregivers' narratives dealt with how the relationship with their FFRPS provider, inspired hope. The very fact that the person who was providing them with support had survived similar difficulties, instilled a sense of hope, encouragement, and increased resilience within caregivers. This finding converges with previous research, which has shown that peer support can lead to higher levels of hopefulness for recovery (Cook et al., 2010; Lucksted et al.,

2008).

5.3.8 Feeling heard and held

All interviewees underscored how important the relationship they developed with their FFRPS provider was. Family caregivers expressed how profoundly important, and healing, it was to feel heard and to have their suffering acknowledged. This finding is consistent with studies which have revealed that the relationship between client and counsellor is therapeutic in and of itself, and is an important predictor of outcome (Del Re et al., 2012; Norcross & Wampold 2011; Zilcha-Mano et al., 2014). Similarly, Mearns and Cooper (2005) assert that the counsellor, and client in crisis, can develop this quality of connection, which provides the necessary psychological holding for clients in extreme states of dissonance. This assertion is supported by findings from a recent qualitative study (Carrick, 2014).

The findings from the present study reveal how much it meant to family caregivers to be asked about themselves, to be heard, and treated with respect and consideration. This finding is consistent with previous studies (Lucksted et al., 2008; Shor & Birnbaum, 2012). The present study builds on previous findings by providing insight into how some caregivers believed that their suffering was inconsequential relative to their family member's illness and therefore they devoted all their focus to their SMI family member. Doing so led to fusion within the relationship and a gradual loss of their sense of self, which is in line with previous research (Murphy et al., 2016). It is well established that fusion and lack of differentiation in interpersonal relationships can have disastrous consequences (Bowen, 1978; Skowron & Schmitt, 2003).

Family caregivers identified how receiving FFRPS alleviated some of the physical and emotional stress they were carrying. Caregivers commonly spoke in terms of the "relief" they felt afterwards from having been able to express their feelings and share their experiences. This process allowed interviewees to become aware of, and in touch with, their own feelings once again, as opposed to feeling "lost" in their family members' SMI. This combination of feeling heard and understood, within a safe relationship, seemed to have had a healing effect. This finding converges with previous research (Carrick, 2014).

Family caregivers spoke in terms of feeling 'held' or contained by receiving FFRPS. Interviewees described the comfort and assurance they experienced in knowing they could talk about the stressful events, which had occurred that week during their FFRPS session, and that even just knowing that, helped them to stay grounded and to be more resilient. The opportunity to speak

openly about mental illness within such a therapeutic space may foster resilience because it is a means through which family members can process their feelings and are provided with an emotional holding for both hope and hopelessness (Flaskas, 2007; Joseph, & Linley, 2005; Power et al., 2016).

5.3.9 Finding my strength

This theme considers how receiving FFRPS led family caregivers to recognise and appreciate the importance of practising self-care, which gradually led to a strengthening of the self and increased resilience. Interviewees elaborated upon how they learned that practising self-care actually improved their relationships with others, and their quality of life. This finding is consistent with previous research (Byrne et al., 2011; McCann et al., 2015; Zauszniewski et al., 2009). The current study extends previous findings by revealing how some caregivers came to realise that they needed to focus on keeping themselves well, so that they could model healthy self-care for their SMI family member. However, one interviewee, who had been supporting her SMI relative for over three decades, described the challenges she experienced as a result of the FFRPS provider's suggestion to practise self-care. This finding lends support to the argument that it is more effective, and more appropriate, to receive FFRPS shortly after one's family member has been diagnosed before patterns of interaction, and expectations, are established.

The majority of family caregivers described how, as a result of receiving FFRPS, and improved self-care, they felt they had grown in strength, self-confidence and resilience. Similarly, previous research has identified how receiving emotional support is associated with resilience and post-traumatic growth among family members who have a relative with SMI (Barsakova & Oesterrich, 2009; Enns et al., 1999, Anuradha, 2004, Greeff et al., 2006). Caregivers described how, this increased resilience, due to FFRPS, had led to an improvement in their ability to cope with difficult circumstances. This finding supports previous evidence that peer support can lead to increased confidence (Fung & Chien, 2002), increased perceived quality of life (Charlesworth et al., 2011; Wang et al., 2012) and enhanced feelings of being in control (Wang & Chien, 2011).

In keeping with Family Systems Theory (Bowen, 1978), and theories of family recovery (Spaniol, 2010), family caregivers described how they had come to realise that it is not only their family member who is recovering from mental illness, but that the rest of the family are also recovering from the shared traumatic experience. Having received FFRPS, a strong common theme of feeling empowered permeated caregivers' narratives and a journey of growth in strength and self-compassion was evident across interviews. This finding is consistent with previous research, which

found that peer support can result in improved self-care and feelings of empowerment in family caregivers (Lucksted et al., 2008).

5.3.10 A liberating shift from fear to trust

This theme considers how receiving FFRPS increased family caregivers' self-awareness and acceptance of their circumstances, which led to improved family relationships. Family caregivers reported that FFRPS assisted them in gaining greater understanding and objectivity. This finding can be understood in terms of how FFRPS facilitated post-traumatic growth. Similarly, Tedeschi and Calhoun (1995) propound that, as a result of trauma, an individual can experience a feeling of growth which goes beyond their previous level of functioning and awareness.

Findings indicate that, before FFRPS, many family caregivers felt overwhelmed by uncertainty and anxiety about how they were responding to their SMI family member. This finding is consistent with previous research (Dixon et al., 2011; Lucksted et al., 2008; Lucksted et al., 2013). Findings from the present study indicate how receiving FFRPS improved family caregivers' self-awareness in relation to their role in maintaining problematic relationship dynamics. For example, some caregivers became aware of how feeling unappreciated had led to feelings of resentment, which were then, inadvertently, taken out on their SMI family member. Others developed insight into how they were, unwittingly, fostering dependency within their ill family member. These findings converge with previous research (Karp & Tanarugsachock, 2000) and are in keeping with studies on family resilience (Cohen et al., 2011; Kalil, 2003; Patterson, 2002; Power et al., 2016 Walsh, 1996). Findings from the present study builds upon previous research by providing insight into how, in order to cope with feeling intolerably powerless in the face of their family members' illness, and due to their own fear of "not knowing what to do", family caregivers unwittingly intensified their SMI family members' struggles, by either adding pressure or withdrawing completely. However, by receiving FFRPS, family caregivers described how they came to experientially know and appreciate the value of simply being kind, present and available to another human being. Family caregivers reported that they were then able to return this same kindness to their SMI family member.

Findings indicate that engaging in FFRPS, enabled family caregivers to see and think about things differently and supported them in becoming more differentiated, and in lessening dysfunctional patterns and establishing healthy boundaries with their SMI family members. Caregivers described how they have learned to take the ups and downs associated with their family member's mental illness less personally. In keeping with Family Systems Theory (Bowen, 1978),

studies have confirmed that differentiated individuals are less anxious (Peleg, 2005; Skowron & Dendy, 2004), and have higher levels of satisfaction in their interpersonal relationships (Klever, 2005; Lampis, 2016; Skowron & Dendy, 2004).

Across interviews, family caregivers reflected on how, as a result of engaging in FFRPS, their acceptance of their circumstances, as well as their trust in their own, and their SMI relative's ability to cope, had deepened. Family caregivers described how FFRPS supported them in releasing feelings of guilt and responsibility and reflected upon how they had developed a greater capacity to surrender to 'what is'. Interviewees described how liberating this was. This finding is consistent with previous research, which found that following a peer support programme, family members of an SMI relative reported experiencing increased acceptance, feeling more empowered, and improved coping skills (Dixon et al., 2011; Lucksted et al., 2008; Lucksted et al., 2013).

Following FFRPS, interviewees reflected on changes they had observed in their relations with their SMI family members. Interviewees reported improved communication, reduced reactivity, and healthier dynamics. Some noted improved functioning in their SMI family member. This finding supports previous studies, which have shown that criticism, hostility and emotional over involvement (high EE) are associated with discord in relationships between SMI patients and those in caregiving roles and are a robust predictor of relapse (Barrowclough et al., 2001; Butzlaff & Hooley, 1998; Patterson et al., 2005; Tarrier et al., 1994). This finding also supports studies that have found that those who experienced post-traumatic growth, have reported that their relationships are somehow enhanced and that they feel increased compassion toward others (Joseph & Linely, 2005; Rosenbach & Ronneberg, 2008).

Examination of the interview data, revealed a sequential journey of recovery and post-traumatic growth across family caregivers' narratives. After receiving care within the FFRPS relationship, and having processed and integrated their own trauma, family caregivers grew in strength and were more 'freed up' to be objective about their role in maintaining the status quo within the family. This sequential journey of recovery culminated in caregivers developing the awareness, and confidence, to replace old strategies of providing care with mutually empowering ways of genuinely supporting their family member. A schematic of how interviewees depicted FFRPS as having catalysed change, is presented in Figure 4.1 (page 81). These findings are in keeping with previous research, which has highlighted the importance of addressing SMI within the context and needs of the whole family (Barrowclough et al., 2001; Barrowclough et al., 2003; Gatsou et al., 2017; Falkov, 2011; Reupert & Maybery, 2014; Tarrier et al., 1994; Wearden, et al., 2000), and are in line with studies, which have

demonstrated how interventions that focus on family relationships have potential to benefit all family members (Fadden & Heelis, 2011; Fallon, 2003). These findings are also consistent with evidence on the importance of integrating trauma (Siegal, 1999; Steele et al., 1997) and are in keeping with the Person-Centred approach (Rogers, 1951), in relation to how clients, when provided with the core conditions, can become self-directing in profoundly wise ways. These findings are also in line with theories of family recovery (Spaniol, 2010).

5.4 Limitations of the Study

It is important to consider the limitations of the current study. Family caregivers were interviewed once after having received the FFRPS intervention and it is possible that recall bias may have occurred (Hassan, 2006). If family caregivers were interviewed before the FFRPS intervention and again after the intervention, the measurement of the impact of receiving FFRPS would have been more informative and perhaps more reliable. To minimise the risk of recall bias a standardised data collection protocol was used, which included giving participants enough time to think and reflect on their answers, as recommended by Hassan (2006).

Another potential limitation is that the present study's findings may have been influenced by volunteer and confirmatory bias and social desirability. Family caregivers voluntarily consented to receive the FFRPS intervention. Research has shown that when have chosen to volunteer for something, we tend to tell ourselves that it was a worthwhile venture (Salkind, 2010). Furthermore, it is likely that family caregivers, who volunteered to receive FFRPS intervention, already had favourable attitudes towards therapeutic interventions and predicted that they were likely to gain from the experience. Interviewees all reported really liking their FFRPS provider; due to social desirability, they may not have wished to report negatively on FFRPS, which was aimed at helping them.

Finally the findings generated by this study are based on a small, purposive sample of individuals who consented to participate. These findings are solely representative of the experiences of this specific group of individuals and therefore are limited in terms of their generalisability. However, in keeping with the aim of the study, the findings' value lies in its depth and richness rather than in its quantity. Although we cannot directly assess, or make claims, regarding the generalisability of these findings, they can be considered valuable in terms of their transferability. The emergence of a sequential journey of recovery, and post-traumatic growth, across family caregivers' narratives, suggests that these findings may hold a broader relevance for FFRPS

participants and may help to explain how such interventions benefit them.

5.5 Strengths of the Study

The current study has a number of strengths. In relation to the study's aims and its contribution to the research literature, to the best of the researcher's knowledge, it is the first study to provide insights into family members' (of individuals with SMI) lived experiences of receiving one-to-one peer support intervention. This study gave family caregivers a platform to express their views and experiences. Its use of IPA as a methodological approach can be considered as a strength. Employing IPA provided an in-depth understanding of interviewees' subjective experiences. The interpretative component of IPA facilitated the identification of concealed meanings in the data. Interpretation is a product of the interaction between the researcher and participant and is only one interpretation. Alternative interpretations of the findings are possible. IPA acknowledges its inherent limitations in a transparent manner. It recognises the centrality of the researcher's biases and presumptions in the interpretation of the phenomena under investigation. Efforts to minimise the impact of these biases and to increase rigour included the researcher's maintenance of a clear audit trail and implementing provisions, such as credibility and trustworthiness checks.

The FFRPS intervention had a high retention rate. Eleven of the twelve participants completed all six sessions. The twelfth participant completed four of the six sessions. A particular strength of this study was that all twelve participants were interviewed and their experiences were captured compared with the typical attrition rate of 33% (Eysenbach, 2005).

As a Psychologist in Clinical Training, the researcher has experience in creating a safe and contained environment to allow individuals to be able to share their experiences. Applying these clinical skills supported interviewees to feel at ease and facilitated the elicitation of rich narratives and in-depth insights.

The current study employed patient and public involvement (PPI) at the consultation level. There is a growing acceptance of the need for more PPI in research (e.g. Domecq et al., 2014). The active involvement of family caregivers greatly enhanced the quality and appropriatness of the present study, and most likely, the participation rates from family memnbers (facilitated by the researcher's increased understanding of family caregivers' perspectives, and a focus on sensitive/meaningful wording on the invitation letters and information sheets).

5.6 Implications for Clinical Practice

Family caregivers have been recognised as a crucially important community resource for those with SMI. Providing family caregivers with adequate support will not only have long-term cost benefits but will lead to improved treatment outcomes (Amir, 2016; Norman et al., 2005). However, findings from the present study highlight family caregivers' unmet needs for emotional support. Findings reveal that having a family member suffer with SMI is a traumatic experience for caregivers, and one which causes a strain within their family relationships. Mental health professionals need to be aware of this so that they can respond in an appropriate and helpful manner.

This study highlights the need to address SMI within the context, needs and experiences of the family in order to facilitate recovery. In an era of limited resources for mental health care, family interventions need to target, and to be responsive to, families' expressed needs. The findings of the present study clearly demonstrate that FFRPS was a beneficial intervention. Given the current dearth of research on peer support for family members of individual's with SMI, this is an important finding. Family caregivers expressed how profoundly important, and healing, it was to feel heard and to have their suffering acknowledged. The significance of genuine understanding in the context of experiential similarity was repeatedly identified as invaluable. Importantly, findings indicate how receiving FFRPS improved family caregivers' resilience and self-awareness in relation to their role in maintaining problematic relationship dynamics. Findings indicate how engaging in FFRPS led to post-traumatic growth and family recovery. However, it is important to note that, for one family caregiver, engaging in FFRPS disrupted and threatened her use of her own well established coping mechanisms and defences, which was distressing for her. This finding highlights the need to forewarn family caregivers, in a therapeutic manner, that by engaging in FFRPS, they may run this risk.

The findings from the present study support the roll out of FFRPS as a very beneficial intervention for family caregivers of individuals with SMI. While the FFRPS providers received remuneration for their time and services, FFRPS is nevertheless a much more cost effective service than any other provided by mental health professionals.

Importantly, these findings shed light on how the needs and preferences of caregivers change over time, and indicate that a tailored approach to meet the families' needs is required, which is consistent with previous research (Drapalski et al., 2008; Jewel & Smith, 2007). For example, the findings suggest that it is much more effective to receive the FFRPS shortly after one's family

member has been diagnosed before patterns of interaction and expectations are established.

The present study sheds light on how some caregivers believed that their suffering was inconsequential relative to their family member's illness, and therefore, they devoted all their focus to their SMI family member, and lost touch with their own needs. This finding suggests that family caregivers may not be aware that they need support, or may not feel deserving of support. The clinical implication of this finding is that mental health professionals may need to be patient, and gently persistent, when offering FFRPS to family caregivers. However, it is encouraging to note that, the fact that FFRPS was developed as a service, seemed to endow family caregivers with the permission to acknowledge their own needs.

The remaining recommendations for clinical practice are offered based upon the suggestions that family caregivers made during interviews:

- Provide more support/funding for caregivers of SMI family members, to promote the sustainability of the role.
- The mental health team should listen more to family caregivers. Interviewees felt that their expertise was ignored or devalued.
- The FFRPS booklet (Appendix L) should be issued to all family caregivers. Interviewees found the booklet very helpful.
- Tailor supports to the family's needs. For example, provide one-to-one peer support to those whose family members have recently developed SMI, and provide group peer support for those who have been family caregivers for longer durations.
- Pair family caregivers, and FFRPS providers, who share similar family situations.
- Provide follow-up support after the FFRPS intervention. For example, monthly/bi-monthly group meetings would be useful in terms of maintaining the benefits gained from FFRPS.
- Provide opportunities for family caregivers to train to become FFRPS providers. The fact that a number of interviewees, without solicitation, expressed an interest in training to become FFRPS providers bodes well for how sustainable this service/ resource could be.

5.7 Implications for Education

Family caregivers for individuals with SMI are only beginning to be recognised as an essential component of care services (A Vision for Change, 2006). Providing adequate support for family caregivers is likely to positively impact on relatives with SMI. It is very important that mental health professionals, and management/decision makers, are educated about the need to provide support to family caregivers, otherwise caregivers may gradually become less effective and possible even a liability.

The findings from the present study provide important insights into how SMI impacts upon families. Caregivers disclosed how intolerably powerless they were rendered by having their family member develop SMI. Analyses revealed how family caregivers struggled with ambivalent feelings, including fear, frustration, grief, anger, and guilt. We need to educate mental health professionals about how SMI can impact upon families, in order to increase clinicians' sensitivity and their ability to support family caregivers by normalising these reactions (the present study's findings have recently been presented at a continued professional development (CPD) seminar for social workers).

Family interactions offer the opportunity to facilitate recovery from SMI, but they also have the potential to hinder recovery (Aldersey & Whitley, 2015; Brown & Weisman, 2018; Reupert et al., 2015). While there is a growing body of literature on recovery of individuals with SMI (e.g. Drake & Whitley, 2014), there is little information about the recovery process in other family members. Findings from the present study reveal how receiving care within the FFRPS relationship, and having processed and integrated their own trauma, family caregivers grew in strength, and in self-awareness, regarding their role in maintaining problematic relationship dynamics. This increased awareness, and confidence, led caregivers to replace old strategies of providing care with mutually empowering ways of genuinely supporting their SMI family member.

Another key educational message, which this study highlights, relates to the importance of the therapeutic relationship, which family caregivers formed with FFPRS providers. While undoubtedly experiential similarity was a hugely significant aspect of this relationship, these findings also highlight how being fully present, and striving to provide another with congruence, unconditional positive regard and accurate empathetic understanding, is enormously powerful and can be viewed as healing in and of itself. Anecdotally, clinicians have expressed feeling inadequate and underestimating the value of providing clients with such a relationship. With mounting

pressures on busy mental health services, it is important that, during supervision or at CPD events, clinicians are reminded of the importance of the therapeutic relationship.

5.8 Implications for Policy

As recommended by existing policy guidelines such as 'A Vision for Change" (Department of Health & Children, 2006), the HSE Mental Health Division Operational Plan 2017 and the National Framework for Recovery in Mental Health (2017), a major goal in terms of service transformation is to move towards more recovery-oriented ways of working. A key objective in terms of achieving this goal is for the services to become more centrally informed by the views, and experiences, of service users and family members. Findings from the present study provide such access to family caregivers' views and experiences. In order to develop more effective services, future policy initiatives should take these views and experiences into account.

An incidental finding of the present study relates to how the stigma which surrounds SMI, contributed to family caregivers' feelings of shame, profound isolation, and their struggle to accept that SMI had occurred in their own family. Future policy initiatives should continue to target the stigma surrounding mental illness and advance educational campaigns aimed at de-stigmatising/normalising mental illness and normalising seeking help.

5.9 Recommendations for Future Research

Given the paucity of research on peer support for family members of individual's with SMI, it is imperative that the effectiveness of such interventions are further explored. In future studies, it would be useful to interview family caregivers before FFRPS, after the intervention and again in six months' time. Doing so would provide more informative and more detailed accounts of family caregivers' lived experiences before and after FFRPS. It would also be valuable to simultaneously interview individuals with SMI, at each time point, to gain insight into their perspectives on how having a family member receive FFRPS may have impacted on them.

Findings from the present study suggest that one-to-one peer support should be provided to those whose family members have recently developed an SMI, whereas group peer support may be more relevant for those who have been caregiving for longer durations. However, this suggestion needs to be empirically evaluated.

As FFRPS is still only a pilot intervention, with only twelve family caregivers having received FFRPS, a qualitative methodology was considered to be the most appropriate means of investigation for the present study. If FFRPS is rolled out on a national level, complementary quantitative and mixed methods research should be conducted. Future large scale studies, ideally, could randomise family caregivers to a waitlist control group, a one-to-one peer support group and a group peer support group for analysis.

The interviewees in this study were all female. This, perhaps, reflects how females tend to provide more care than their male counterparts (Miller & Cafasso, 1992; Yee & Schulz, 2000). However, it is important that future studies interview male family members in order to provide insight into their lived experiences.

A vitally important avenue for future research would be to investigate why so many family caregivers declined the invitation to participate in FFRPS. Future researchers could explain to family caregivers, who are not interested in FFRPS, that this is a phenomenon the services are trying to better understand. Questions could include whether they would have been more receptive to being approached directly by a peer? Or would they have been willing to engage if there was no caveat of having to be interviewed afterwards? It is concerning that the family caregivers who consented to participate, may be among the more psychologically healthy in that they were able to recognise their need for support and were able to accept the offer for same. Those less psychologically healthy may be in much greater need of the service and a way should be found to support them.

An important area for future investigation is to explore FFRPS providers' experiences of providing FFRPS. It would be very informative to re-interview family caregivers who received FFRPS and then went on to become FFRPS providers. Another possible avenue for future research would be to investigate whether a peer support helpline for family caregivers would be beneficial and feasible (either as an add on or as a stand-alone intervention). A helpline may be more acceptable as it offers more discretion and could be a convenient, a less intrusive and a more attractive way of accepting support. Following FFRPS, a peer support helpline could provide a supplementary form of support.

5.10 Critical Reflection from a Personal Perspective

As the primary researcher of the current study, it has been necessary to remain mindful of, and to acknowledge my own centrality in this research study. While my interests, epistemological position and preconceptions were previously outlined in Chapter 3, it is important to further reflect on the role that my life experiences, expectations and personal reactions played throughout the course of this project as it is possible that these may have influenced the interpretative process and compilation of the overall report.

My family member experienced a period of mental illness, although it was not as enduring, nor severe, as were the illnesses that befell the families of those I was interviewing. However, what I did share in common with interviewees was the pain of feeling helpless in the face of a loved one suffering. I too struggled with guilt, frustration, resentment and with the exhaustion of ambivalent, consuming, and restless feelings. The fact that supporting others with their mental health is supposedly my area of 'expertise' made these feelings all the more acute.

When our lecturer issued an email explaining that the FFRPS pilot intervention needed to be researched, I was very mindful of how I was drawn towards volunteering. Additionally, as a Psychologist in Clinical Training, and as a person who has engaged in personal therapy, I am aware that I am biased in favor of therapeutic interventions. Due to my personal and professional biases, I was keenly aware of the need to monitor my own reactions throughout the research process. As part of my clinical training, I am encouraged and supported to regularly reflect on my practice. Adopting a reflexive approach to this research study was both necessary and useful. For example, during an initial interview, I bristled at an interviewee's description of mental illness as 'selfish'. While journaling, I reflected on this and realised that this was an example of my personal prejudice, impeding my ability to receive another's lived experience. As a result, I was better prepared to be more receptive and less judgmental the next time an interviewee shared an experience, which differed from my own or challenged my views.

I thoroughly enjoyed meeting the family caregivers, listening to their stories, and gaining insight into their lived experiences. The majority of interviews were intense and emotionally charged. I felt privileged, and humbled by, interviewees' willingness to share such intimate and painful experiences. I was repeatedly struck, and inspired by interviewees' love, resilience and strength. I found myself learning from their acquired wisdom, and deeply moved by their

experiences. I was astounded by how much interviewees had gained from just six sessions of FFRPS. I did not disclose my own personal experience to interviewees because I did not want to detract the focus of the interview from their experiences. However, one interviewee, after the interview's close, asked if I had experienced mental illness within my own family and I shared I had.

While carrying out the interviews and extracting themes, I became aware of how difficult it was to avoid being influenced by my existing preconceptions of what it means to have a family member with mental illness. Furthermore, it was challenging to engage in the process of 'bracketing' information from one interview to another, in an effort to approach each interview with an equally open mind. I struggled most during the data analysis phase, I frequently felt overwhelmed. I wanted to do justice to the interviewees who had entrusted me with their lived experiences. At times, I felt conflicted and constricted when attempting to accurately portray their individual narratives while simultaneously distilling their narrative content into a manageable, coherent collective account.

In terms of my clinical work, this research has reinforced the importance of the therapeutic relationship and has underscored how, first and foremost, it is a connection based on shared humanity. This research has also reawakened my faith in the Person-Centred approach. Conducting this research has heightened my awareness of family members' suffering and the importance of considering the person within their family context. This research has prompted me to think more systemically when formulating.

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Appendix A
Participant Information Sheet

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

ETHICS APPROVAL NO:

Title of Project
Experiences of Receiving FRIENDS Family Recovery Peer Support Intervention for Family Members of Individuals with Mental Illness

The Study
One of the current challenges for service delivery in the area of mental health is the support of family members who support individuals with mental health difficulties. This study seeks to explore the effectiveness of the FRIENDS Family Recovery Peer Support Service for family members of people using the Mid-West mental health services.

What is FRIENDS Family Recovery Peer Support?
The FRIENDS Family Recovery Peer Support is a system of receiving support from someone who also has a family member with a mental health difficulty. The Family Recovery Peer Support providers have been trained to provide such support and can also relate empathically through having a shared experience. Unlike clinical help, peer support helps people to understand each other because they've 'been there', shared similar experiences, have learned from experience and can model for each other a willingness to learn and grow.

Why have I been asked to participate?
You have been invited to participate in this research because you have volunteered to receive FRIENDS Family Recovery Peer Support**.** You were invited to receive FRIENDS Family Recovery Peer Support because you have a family member who was referred to St. Anne's mental health services during the past 18 months.

What will I have to do as a Participant?
As a participant, the focus of the study is to assess your experience of receiving the FRIENDS Family Recovery Peer Support. You will complete a questionnaire pre and post your experience (approx. 10 mins) and participate in an interview on completion of the experience (at least 30 mins but no more than 1 hour).

Do I have to take part? The answer is no! – participation is voluntary and there are no consequences for not participating.

What are the risks?
There are no known risks involved in the study but mental health can be a sensitive subject for people. As such the appropriate support strategies will be outlined. It is important to note that you are under no obligation to participate in this study and are free to withdraw at any time throughout the study.

Are there any benefits from my participation? There will be no direct benefit from participation; individuals will not be offered any monetary or other rewards for their participation. However, findings from this study may lead to, and inform, a larger roll out of

the FRIENDS Family Recovery Peer Support Service and provide a model of best practice in terms of supporting relatives.

Confidentiality
This study has been approved by the HSE Mid-Western Regional Hospital Research Ethics Committee. All information will be kept confidential. All information gathered will be stored in a secure location with the use of passwords. Access will be granted to the researchers and supervisor only. No information about you, the subject, will be indentified in the final report. Participants will remain anonymous throughout the study and any identifying information will be ommitted from the final write-up. You may decide to withdraw from this research at any time. If you choose to withdraw from the study, you should notify the researcher. There are no consequences if you withdraw from the study. If you wish not to grant consent to this study, you data will be exluded from the analysis and will be correctly disposed of.

Thank you for taking the time to read this. I would greatly appreciate if you would consider participating in this study.

If you have any further questions about the research, please contact:

Researcher Contact Details: Deirdre Reynolds — Department of Psychology, University of Limerick

Email: 12022659@studentmail.ul.ie

Phone: 061 202663

Researcher Contact Details: Jennifer McMahon — Department of Psychology, University of Limerick

Email: Jennifer.McMahon@ul.ie

Phone: 061 202663

Appendix B
Shine Information

What is Shine?

Shine is the national organisation dedicated to upholding the rights and addressing the needs of all those affected by mental ill health, through the promotion and provision of high-quality services and working to ensure the continual enhancement of the quality of life of the people it serves.

Do I have to pay for Shine services?
Only for membership and counselling (both on a sliding scale).

Membership
Membership is encouraged and this allows members to have first priority in gaining access to Shine events. Individual membership is €10 per calendar year, full family membership is €20 (for up to 3 family members), associate membership is free and student/volunteer membership is €5.

What is the role of the Regional Development Officer (RDO) or Support and Information Officer (SIO)
The RDO or SIO **is your main point of contact in your local region**. They can provide information, listening, support and training. They can offer you an Individual Support Meeting (ISM), which is unstructured, person centred, confidential, solution focused and individually tailored. It may be that one is sufficient with other information and supports. You may decide to meet the RDO/SIO again to follow-up and/or you may be referred to another service within Shine or externally.

What are the benefits of accessing the RDO?
The RDO can work with you in achieving appropriate and realistic expectations around support, often at a point of crisis. They can give up-to-date information in relation to the local services, teams and resources and how they work. The RDO can provide support in communicating issues, concerns and needs to assist in maximising an appropriate outcome, which is unique to each individual and family.

How do I know what I say is private?
Shine has clear confidentiality and privacy policies in line with best practice and the law in which all staff, facilitators and volunteers are bound to uphold.

What is a Shine Support Group (Where are they located and when)?

Peer Support Group
The Peer groups that Shine offer are mutual recovery and social support groups which provide a safe place for people with mental health issues to speak openly and in confidence about their feelings and issues regarding all aspects of life, recovery and challenges that they may be on a day to day basis. There is a strong emphasis in the support groups on a positive outlook and approach in overcoming life challenges. Groups are facilitated by a Peer Facilitator and supported by the RDO in your region. People can access one-to-one support (ISM) from the RDO and attend the support groups.
Venue, Date and Time

Ennis: Every Tuesday at 7pm, Community Centre, Chapel Lane, Market Place, Ennis

Kilrush: Every Thursday, 6pm, Kilrush Family Resource Centre

Limerick: Every Wednesday, 7pm, Pastrol Centre, Denmark St, Limerick

Nenagh; 2nd and 4th Thursday, 7pm, Aras Follain, Tyone Rd, Nenagh

Relatives Support Group
The Relatives Support Groups that Shine offer meet on a monthly basis and provide a confidential place for family members and friends to meet and share their experiences. Practical steps towards recovery, information and peer support are the key facets of these groups. Guest speakers can present on a variety of different topics. People can access one-to-one support (ISM) from the RDO attending the support groups.

All group meet at 8pm.

Ennis: 1st Thursday each month, Gate Lodge, Gort Rd, Ennis, Co. Clare (except August)
Nenagh: 2nd Wednesday each month , Aras Follain, Tyone Rd, Nenagh (except August)
Limerick: 1st Wednesday each month, Social Services Centre, Henry St, Limerick (except August)
Thurles: 4th Thursday each month, St Mary's Health Centre, Thurles (except August)

How can I attend the group in my local area?
Please contact the Regional Development Officer to ensure the group is as advertised and get additional support (also see below for details or visit www.shine.ie).

Mid-West Regional Development Officer: Ann Marie Flanagan, Mobile: 087 7878222, email: aflanagan@shineonline.ie

What other supports and services are available to me within Shine?

Education and Family Supports Initiatives
Shine provides a range of education and family support initiatives, including support and education courses. The education courses are designed to help supporting relatives of people with mental health issues to learn more about their own recovery. The education courses concentrate on the specific needs of the relative through the promotion of self-development, self-help and recovery strategies. Your nearest Regional Development Office will inform you of upcoming family support initiatives.

Recovery and the Family Education course is designed to support the recovery and well-being of family members supporting a person with self- experience of mental health issues. It takes place over 7 weeks, 2 hours per week.

Education and Peer Supports
Shine co-produces and offers education and supports to people experiencing mental health issues such as **Finding My Way (designed and facilitated by qualified Peer Facilitators)**, Taking Control and WRAP. The supports concentrate on assisting the person to gain skills in self-help and recovery strategies. Ask the Regional Development Officer for upcoming courses in your area.

On-line Information Resource
A user-friendly website with up-to-date information for persons with self-experience of mental ill health, their caring relatives, the general public and healthcare professionals. To learn more, visit the site at www.recover.ie

Email Support Service phil@shineonline.ie
This service acknowledges that sometimes it is easier for people to write an email rather than pick up the phone. Anyone in distress can email SHINE at any time. We endeavour to respond to emails within a 24-hour period between Monday and Friday. Emails received by phil@shineonline.ie are viewed and responded to by trained psychotherapists. The service is confidential and reliable.

Outside the Mid-West
Counselling
A confidential, affordable, safe and professional service is provided by trained accredited counsellors available in Dublin, Cork available to everyone nationally if willing to travel.

Resource Centres
Shine runs two Resource Centres in Dublin and Cork. These centres are run in partnership with members and provide social, vocational and recreational support to members throughout their recovery.
Basin Club: The Basin Club in Dublin is a peer driven resource centre for people with self-experience of mental ill health. It operates within an ethos of cooperation and partnership. The Basin Club is located at 39 Blessington Street, Dublin 7. Telephone: 01 8601610.

Basement Resource Centre: The Basement Resource Centre in Cork is a peer driven resource centre for people with self-experience of mental ill health. It operates within an ethos of cooperation and partnership. The Basement Resource Centre is located at 14A, Washington Street West, Cork. Telephone: 021 4226064.

Appendix C
Participant Consent Form

ETHICS APPROVAL NO:

Participant Consent Form

Title of Research: Experiences of Receiving FRIENDS Family Recovery Peer Support Intervention for Family Members of Individuals with Mental Illness

Please read the following questions and tick the appropriate yes or no box. Please sign the bottom of the page if you consent to participate in this study.

	Participant	
	Yes	*No*
I have read and understand the participant information sheet.		
I understand what the study is about and what the results will be used for.		
I am fully aware of all procedures and of any risks and benefits associated with the study.		
I know that my participation is voluntary and that I can withdraw from the project at any stage without giving reason.		
I am aware that my individual results will be kept confidential and that a pseudonym will be used to protect my identity.		
I am aware that my interview will be audio recorded and will be deleted after it has been transcribed.		

Participant (Block Letters):

_____

Signature: _____

Date: ___ / ___ / _____

Appendix D:
Invite Letter to family caregivers

Dear family member,

We are delighted to be able to let you know about the NEW family peer support services being piloted here in X Mental Health Services for family members. FRIENDS Family Recovery Peer Support Service will support family members of individuals with mental health difficulties.

As you know yourself supporting a relative with mental health issues can create a need for family supporters to have your own support needs. For several years now families have identified a gap in the service when it comes to their supporting needs and we hope that that this service will provide much needed support for you in a safe and confidential manner. This service will be the first of its kind to be run by the HSE Mid West through St Anne's Community Mental Health Service in collaboration with Shine: Supporting People Affected by Mental Health, Aras Folllain Peer Support Centre and trained family members. It is hoped that this pilot if successful will be offered to all families supporting their relatives accessing Community Mental Health services in this region and eventually nationally.

This innovative pilot service offers 6 one hour (free) sessions of family recovery peer support. This means that you will meet a trained individual who is supporting their relative with a mental health difficulty. The one hour session will most likely take place every fortnight between the hours of 9-5pm so for example 12pm-1pm in a private room on the grounds of St Joseph's hospital or in South Hill Community Centre.

This pilot service will be evaluated by University of Limerick Deirdre Reynolds Psychologist in Clinical Training to ensure the service effectively offered peer support and helped. It is hoped you accept the offer of this free, new innovative family peer support service. We want you to know we take on board the feedback families give us on the need to be supported. To this end in working in partnership with a number of families and other agencies supporting families since 2014 the HSE Mid-West hopes to continue to enhance the services and supports available to you and your relatives accessing mental health services.

For the pilot, places are limited so please contact us by 29/4/17 date to ensure your place in the service, to arrange an initial meeting to complete the short questionnaire and answers any questions you may if you choose to access this service.

We are looking forward to hearing from you,

Kind Regards,

Appendix E
Interview Schedule

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Qualitative Interview Script

Title of Project

Experiences of Receiving FRIENDS Family Recovery Peer Support Intervention for Family Members of Individuals with Mental Illness

As you know my name is Deirdre Reynolds and I am a researcher at the University of Limerick

The purpose of this research project is to understand your personal experience of participating in the FRIENDS Family Recovery Peer Support Service.

Before we begin:

- To ensure that we aren't disturbed during the interview I am going to turn off my mobile phone. Can you do the same? We should not be disturbed during the interview but if we are, I will turn off the voice recorder to deal with the interruption.

- Feel free to interrupt or ask for more information and let me know if you need to take a break during the interview.

- I am interested in your opinions and personal experiences; there are no right and wrong answers to the questions. Is that ok?

Again, may I please have your permission to record this interview?

Participant Information

  - What has been your experience of living with/supporting someone with mental health difficulties?

- How long have you been of living with/supporting this family member with their mental health difficulties?
- When did your family member begin engaging with (name of mental health service?
- Can you tell me a little bit about why you participated in the FRIENDS Family Recovery Peer Support Service?

- **Experience of Family Recovery Peer Support**
  - I'm interested in hearing about your experience of receiving FFRPS?
  - Have you noticed any differences in your relationship with this family member since attending the FFRPS? If so, please describe
  - Please tell me about what you found were issues or challenges when receiving Peer Support?
  - How did you relate to the person who was providing you with Family Recovery peer support?
  - What recommendations would you offer to the developers of this service?

- Additional Comments
  - Would you like to add anything else about the FRIENDS Family Recovery peer support service?

Examples of follow-up prompts to open ended questions

- Tell me more about that
- Can you say more about that?

Thank you for participating in this interview.

Interviewer's comments:

_____
_____
_____
_____
_____
_____
_____
_____

Reflective notes:

_____
_____
_____
_____
_____
_____
_____
_____

Appendix F
Debrief Form

ETHICS APPROVAL NO:

Debriefing Sheet

Title of Project

Experiences of Receiving FRIENDS Family Recovery Peer Support Intervention for Family Members of Individuals with Mental Illness

Self-Care

If participating in this study on the FRIENDS Family Recovery Peer Support Service has caused any personal distress we would encourage you to contact any of the following services:

- ***SHINE – email: Midwest@shine.ie, telephone: 087 787822 Mon-Fri 9.30 – 5.30pm
- The Samaritans – Free counselling service 116 123

***Shine is an agency that aims to empower people with mental ill health and their families through support, information and education. We also advocate for social change, promoting and defending the right of all those affected by mental ill health to equal rights and quality services.

For all other concerns relating to the study you may contact:

Researcher Contact Details: Deirdre Reynolds
Department of Psychology
University of Limerick

Email: 12022659@studentmail.ul.ie

Phone: 061 202663

Researcher Contact Details: Jennifer McMahon
Department of Psychology
University of Limerick

Email: Jennifer.McMahon@ul.ie

Phone: 061 202663

Appendix G

Adjustments made following pilot interview

- Realised the importance of emphasising that I am interested in interviewees' opinions and personal experiences, and that there are no right and wrong things to say.
- Open with broad open-ended question (e.g what has been your experience of living with/supporting someone with mental health difficulties?
- Refer to 'mental health difficulties' rather than mental illness.
- Allow interviewees lead the conversation by telling me about what is important rather than me asking a lot of questions.
- Use encouraging phrases such as 'I'm interested in hearing about your..' and 'tell me more about that'
- Use schedule flexibly.

Appendix H
Extracts from Reflective Journal

28/10/16

I attended a meeting with FRIENDS steering group committee. It was great to meet everyone but there is still an awful lot to get my head around. I was struck by how committed the FRIENDS steering group committee are and I'm feeling the pressure to conduct a good piece of research; it's my first time having to carry out research 'for' a group so I suppose it's a pressure I'll have to learn how to adjust to, while remaining objective in my researcher role. It's great that I have X to consult with and seek supervision from. I'm delighted that minutes from the meeting will be sent around as, even though I took notes, I'm eager to ensure I didn't miss, or misinterpret, any points. The group proposed a qualitative approach to the research given the small numbers involved. Lots of practical issues still need to be discussed and ironed out. For example, regarding which method of analysis to use. Jennifer seems keen on thematic analysis, but based on what the committee members and family caregivers said, I think IPA may be more suitable. I need to read further around potential methodologies and come up with a good solid rationale.

22/3/17

I spoke with the mental health team social worker again today, she has been incredibly supportive and helpful. I'm delighted, and relieved, to hear that we finally have 12 participants. I was really reluctant to go ahead with any less due to the typical attrition rate of 33%. I'm really surprised by how difficult it has been for X to recruit family members, I wonder if the prospect of having to be interviewed by someone they've never met, about something so personal, is what's off-putting? I've another FRIENDS steering group committee meeting in Limerick coming up; it's hard to fit in around placement in Dublin.

15/11/17

I interviewed 'Edie' today. From the minute I met her, I felt comfortable in her presence. She has such warmth and strength of character. She was so engaging and articulate; she made my job easy. I'm not sure exactly what I'd expected, but Edie wasn't it! Strolling to get a cup of tea together before the interview was a good idea as it allowed us a chance to break the ice and to become more comfortable with one another. It was a fascinating interview but I was exhausted afterwards! Edie is a force of nature and spoke candidly about difficult issues. Although I'm keen to collect all the data while in Limerick, I definitely mustn't arrange more than two interviews a day. It was great not having to be concerned with or restricted by time today.

17/11/17

'Natalie' didn't show up for our meeting yesterday… this is the second time. I'm not sure how best to handle it. I'm curious about what's driving her ostensible ambivalence?. I want to assure her that I'm interested in hearing about her experiences good, bad or indifferent. Maybe she's anxious or reluctant to meet with a stranger to discuss something so personal? Maybe she feels obliged she has to say something in particular about FFRPS? I'll discuss it during my next supervision. Alison has also stopped returning my messages and didn't respond to my call. Last time we spoke, she couldn't agree on a day to meet because she has such a hectic schedule. I'm wondering if she'd be more comfortable with a phone interview? I'll ask about this during supervision.

23/11/17

I had a great interview with 'Claire' today. I am in awe of her resilience. She was lovely to get to know. I found it remarkable how good humoured, personable and considerate she is, given the chronic nature of the hardships she has experienced. Claire provided rich insights into her experiences, lots to reflect on. When she was recounting her daughter's mental health history, I found myself becoming very curious and I before I knew it, I'd asked a couple of questions, the type I would during an intake interview, and then I had to remind myself of my

role as a researcher in this situation. It felt a little strange; I wonder what was activated in me? I think I wanted to fully understand so that I might be able to help or give back in some way. I have to watch this in myself.

15/02/2018

I'm really struggling with this findings chapter. From the data generated by the interviews, it is clear that these participants are very insightful, and have spent time reflecting upon, and analysing, their experiences (based upon what they have said, it seems as though the FRIENDS Family Peer Support facilitated their growth in awareness and insight). As a consequence, I am finding that I'm having to do less analysing than I had anticipated, and therefore I'm somewhat concerned that it's reading more like a thematic analysis rather than IPA? However, I am very much still interpreting and adhering to IPA guidelines. I'm very attached to the direct extracts from the transcripts that I've included. I think hearing directly from the interviewees is by far the most persuasive and potent way to gain insight into their lived experiences. However, my supervisor is suggesting that I'm including too many quotes. I'm also really starting to worry about the word count. It seems impossible to cover it all in 10,000 words. I think I need to step away from this chapter by working on another and hopefully can return to it with fresh eyes.

Appendix I

Examples of IPA Analysis Process: "Leah" Interview

- I = Interviewer
- P = participant
- PS = name of the FRIENDS peer supporter

Emergent themes		Original Transcript	Exploratory comments
	I	So thanks …… once again for coming to meet me. My main question is that I would love to hear about your experience of receiving the FRIENDS peer support	
Feeling desperate and powerless The relief of receiving PS Being validated as a 'human	**P**	I [don't know where to] start. i knew i needed some sort of support and we were at a point where we were absolutely desperate but it's something i'd never saw before, you know, you dont know where to start, you don't know who to ask, you dont know where to go, and of course if you were in an normal, an ordinary sort of situation, you'd have the capacity to think 'maybe if i go down that avenue' but when your in that desperate situation you are so bogged down by it, so when it [the FRIENDS Peer Support sessions] was suggested to me i said 'yeah ok, let's see what this is like and it was....i came out of the first session and i felt....very different than when i went in so it was absolutely brilliant even just from the word go. It's partly through speaking to someone who has been through something similar but it's also somebody recognising how desperate things are for you because a lot of the time, doctors and professionals they know what you are going through but they are dealing with a mum, a family, this was dealing with me as a person, as a human being with rights and we do you know, the whole time i've been dealing with Rita emmh, i've been... feeling like, you can't, you don't want to feel this way but you feel like a victim and you feel like why is this happening, what have i done and you start feeling bad because you think you've done something. when i spoke to PS, it kind of cleared up a way of dealing	Clear sense of confusion & struggle, <u>feeling lost in it?</u> *Repetition of word 'desperate' conveys feelings of powerlessness and unbearable stress.* *…. The pause perhaps conveys the difficulty in finding a fitting description for how different she felt afterwards.* The relief of 'speaking to someone who has been through something similar and of somebody recognising how desperate things are for you' <u>Being seen, heard and recognised as 'a person' rather than just a mother and being validated as a 'human being with rights' seems hugely important.</u> *Hesitation and use of 'can't' conveys reluctance and inner conflict around speaking negatively of her daughter/* feeling like a victim

being with rights' inner conflict around speaking negatively of her daughter feeling like a victim increasing awareness and empowerment		with it, she talked about the triangle [i.e.Transactional Analysis and the Karpman Drama Triangle] and i've realised that if i pull myself out of that and be none of these [roles of victim, persecutor, rescuer], i can handle things much better, it gets you onto the right track, it really does. . Sorry I'm absolutely …… …… but absolutely, i'd recommend it to anybody, the sessions, it was just enough, i think,the 6 sessions was just enough, for me, i felt i was able to talk about anything. She told me who I could go to [names of available support services], you don't always hear about these things, you don't always hear about these people that are there to help. it's just.....it's invaluable, it's the best thing i could have done was to go and see her, seriously, it's vital. it is vital.	Growing awareness and sense of empowerment. *At a loss for words to express how much the intervention benefitted her before landing upon 'vital', which she repeats to emphasis it.*
	I	You mentioned that after the first session you felt different in yourself?	
	P	Yes.	
	I	Tell me a bit about it.	
Feeling alone Worry about how her husband and how he is being impacted by it inner conflict around admitting the negative impact that her	**P**	i did feel like i was alone Even though obviously me and my husband Mark, my husband isn't Ritas dad…… there's not much contact but Mark is, he's incredible, Rita adores him and they get on brilliantly and he's so patient and he's so strong and everything else, he's so gentle. ……. I want him to go to something like this as well. …… this was just me and obviously the nature of it is about the person who is …… and has to be about the person who is …… but I do think he needs something because he is, at times he is struggling, you know, and …… he's the sort who just gets down, quite down about it, and he doesn't, he doesn't shout. He doesn't. He just gets down and I can see it happening with me. I've got a completely different attitude now. You know she's quite ..... the nature of her whatever it is we don't know what's going on. She's seeing a psychologist at the moment and we're hoping that it's close to getting some answers really but it obviously	Feeling alone Concern for her husband and how he is being impacted by it. *Once again reluctance to speak negatively of her daughter. Trails off after saying 'she's quite .....'*

daughter's behaviour and feelings of protectiveness the PS intervention has provided her with a greater sense of perspective and improved coping skills Strengthening of self and of healthy boundaries. abusive aspect of the relationship Chaos and unpredictability and the emotional toll it has taken. Renewed sense of clarity and self-confidence from the PS sessions Inspired by the PS and by what she has lived through. The comfort in realising you are not alone and of having reactions and feelings normalised. Relentless worry, self-criticism, guilt, feeling responsible and self-judgement.		for everyone's sake which. she's quite.....the nature of her illness, she's very manipulative. …, she's very, everything's about her. Obviously I know this happens and it's enabled me to not get wrapped up in that and to say it's stopped me getting into arguments about it i'm now seeing it as a problem that she's going through, how can i put it? i pull myself away from it, it's like im saying ok, this is the nature of her problem, i haven't done anything to trigger this, nobody has done anything to trigger this, she's telling us, we've done things to trigger this but i know we haven't and i can deal with it, in a completely different way and i can stay calm and i'm more firm, more ……. , not a nice thing to say. Don't say that to me again please. I don't want to …… Whereas in the past I would have said "What did you say that for" and get upset, and then she would get, she [loves] it. It's not that she loves the attention. She needs it and she …… all the time, right, and I was, if I …… she's trying to get attention in any way she can. So even if it's bad attention, she's going for it. So since talking to PS she said something very similar and now i don't rise to the negative, i just cut it short. I always did do the positive reinforcement the praise and I love her …… but this, it was the negative attention that was getting me to …… I couldn't cope with it. It was just, it was exhausting. You know you'd be lying awake at night worrying about just the next day. How it's going to be. You know just the aggression with her and the violence and then she goes from being aggressive and violent and she's physically hit me and things like that. So it goes from that to being, within two minutes she …… this sweet little …… you know 'I love you mum'. Are you OK? …… and it's on an emotional level, I can't deal with it. It's impossible. So PS taught me to see it for what it was and to, because as she says if you're completely embroiled in this and completely emotional about this you are not helping anyone because you can't support someone when you can't deal with yourself. So, yeah, she's incredible. She's an incredible woman. I couldn't believe the things that she told me and, yes, she's a great inspiration and just great advice and also the feeling that you are not on your own. Other people are going through this thing that you are going through, sometimes ten times worse, sometimes not, but	Describes how the Peer Support intervention has provided her with a greater sense of perspective on it 'it's enabled me to not get wrapped up in that'. Increased sense of Leah being able to healthily separate herself from it 'i'm now seeing it as a problem that she's going through, how can i put it? i pull myself away from it'. A lessening of Leah's sense of guilt and responsibility 'i haven't done anything to trigger this'. and improved coping skills 'and i can deal with it, in a completely different way and i can stay calm and i'm more firm'. Strengthening of self and of healthy boundaries. Strengthening of self and of healthy boundaries. *Use of 'exhausting' conveys how worn down she was by it.* ?Begins to express the abusive aspect 'she goes from being aggressive and violent'. Describing how chaotic and nonsensical it Sense of enmeshment? Sense of unpredictability and chaos. *Shares the emotional toll it has taken on her 'on an emotional level, I can't deal with it'.* Renewed sense of clarity and self-confidence from the support sessions 'PS taught me to see it for what it was'. Inspired by the PS and by what she has lived through. Once again, the comfort in realising you are not alone. The comfort and reassurance of having her reactions and feelings normalised. Relentless worry, self-criticism, guilt, feeling responsible and self-judgement.

The all-consuming nature of living with it. Vacillates between defending herself and defending her daughter.		everybody has the same, the reactions that we have …… and that we're healthy and that it's to be expected because when, you know, we were trying to deal with her initially I would think that i shouldn't have said that, should I have done that?. I'm a bad person, I'm a bad mum. I shouldn't have told her off for that. This is what happens. You get wrapped up in it because everything, the whole day is on an emotional edge because you are waiting for something to happen. You know it got to the point where Adam does, he took, he's on early retirement, but he does voluntary work, gardening work, for X…… He does a couple of days a week and it got to the point where …… and it's horrible for him and it's horrible for me. She just has this, I think it's a …… separation anxiety …… She was very sick when she was very little from a baby to a toddler and I think it may have something to do with that. It's a separation anxiety thing but because there's a big resentment towards me as well for some reason although I'm the one that, I've been there all her life and it's just this resentment all the time. She doesn't mean it.	Sense of foreboding, walking on eggshells? The all-consuming nature of living with it 'everything, the whole day is on an emotional edge because you are waiting for something to happen'. *Vacillates between feeling the need to defend herself 'I've been there all her life' to defending her daughter 'she doesn't mean it'.*
	I	I know, I know.	
gaining more objectivity	P	And you know we've got, this, receiving the Peer Support taught me that this isn't a place …… It's just the nature of whatever it is that's going on with her. All this and you may have to deal with it in a completely different way. Step right back from it and, I don't know, I can't ……	Seems to be attempting to communicate that receiving the Peer Support has helped her to gain more objectivity.

Appendix J
Ethical Approval Letter

Ospidéil OL
UL Hospitals

Ospidéal na hOllscoile, Luimneach
University Hospital Limerick

Quality & Safety Department,
University Hospital Limerick
Dooradoyle
Limerick.

Tel: 061 482519

9th February, 2017.

Dr. Jennifer McMahon,
Lecturer in Psychology of Education,
DM-035,
Faculty of Education & Health Sciences,
University of Limerick.
Limerick.

Re: Protocol Title:
Evaluation of the FRIENDS (Family Recovery Initiatives by Engaging, Networking and Developing Supports) Family Peer Support Service.
REC Ref: 037/17

Dear Dr. McMahon,

I am in receipt of your proposal as above submitted for review by our Research Ethics Committee. I have reviewed the contents of same.

I wish to advise that I have given your study Chairperson ethical approval.

You should note that your study cannot commence until you also receive AON approval which will issue from the Quality and Safety Department shortly. You are obliged to inform us as soon as your study is completed or if it terminates early for any reason.

I wish you every success with your study.

Yours sincerely,

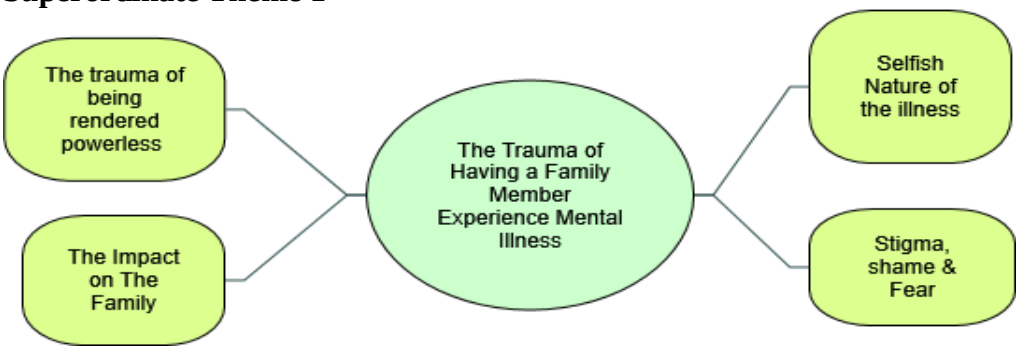
Pat Dillon,
Consultant Anaesthetist,
Chairperson, Research Ethics Committee.

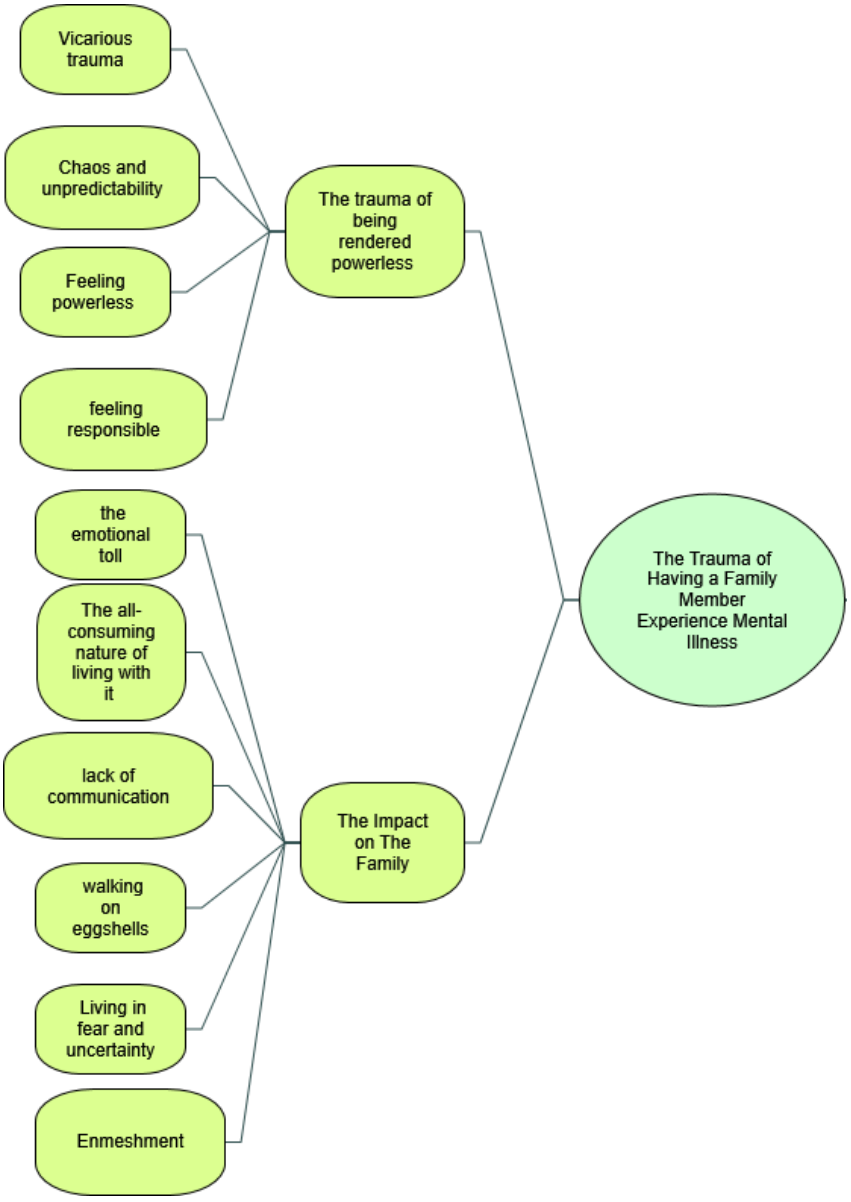
ULH
Caring, Courteous and Professional

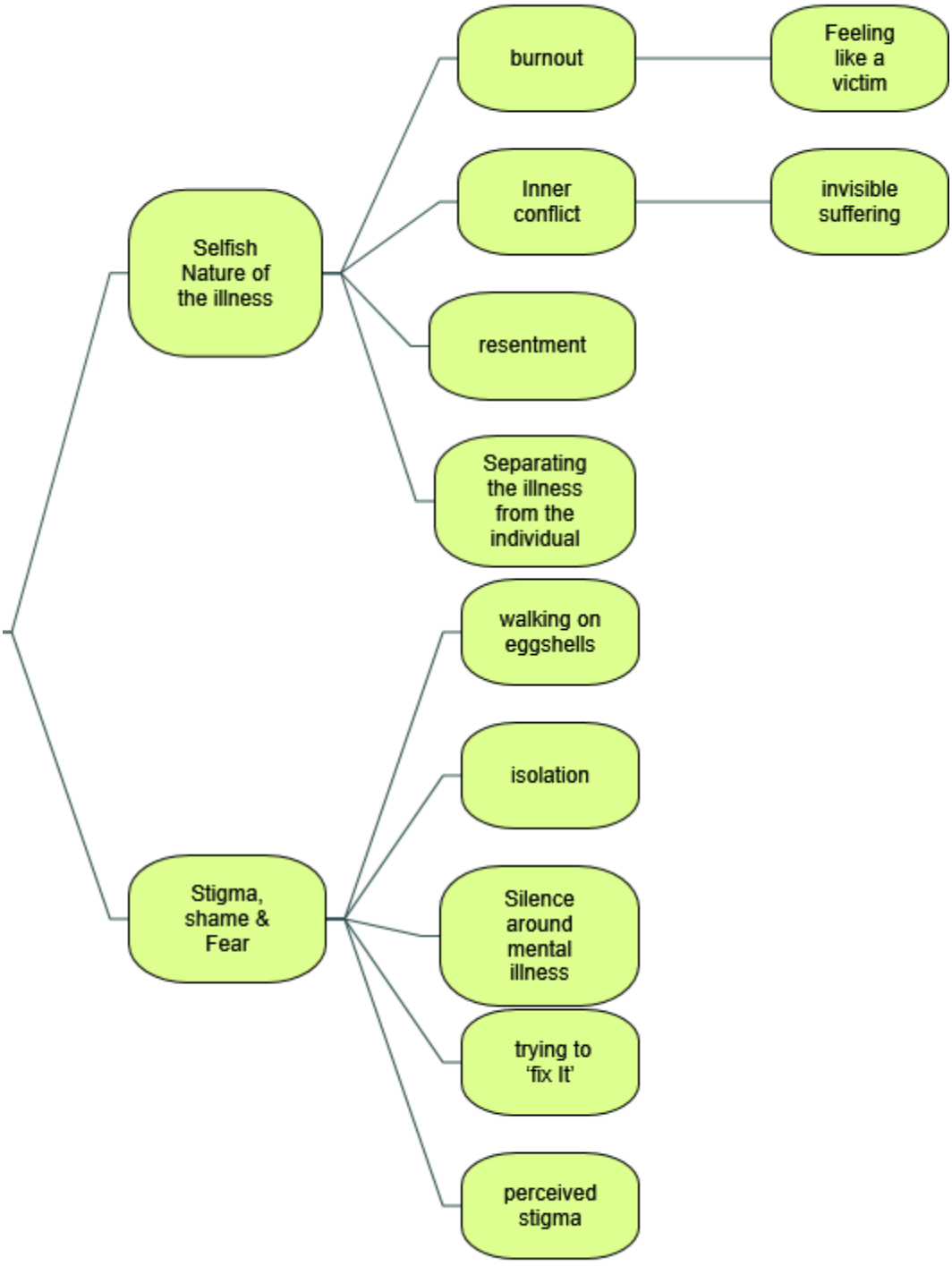
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Appendix K
Conceptual Map of Themes

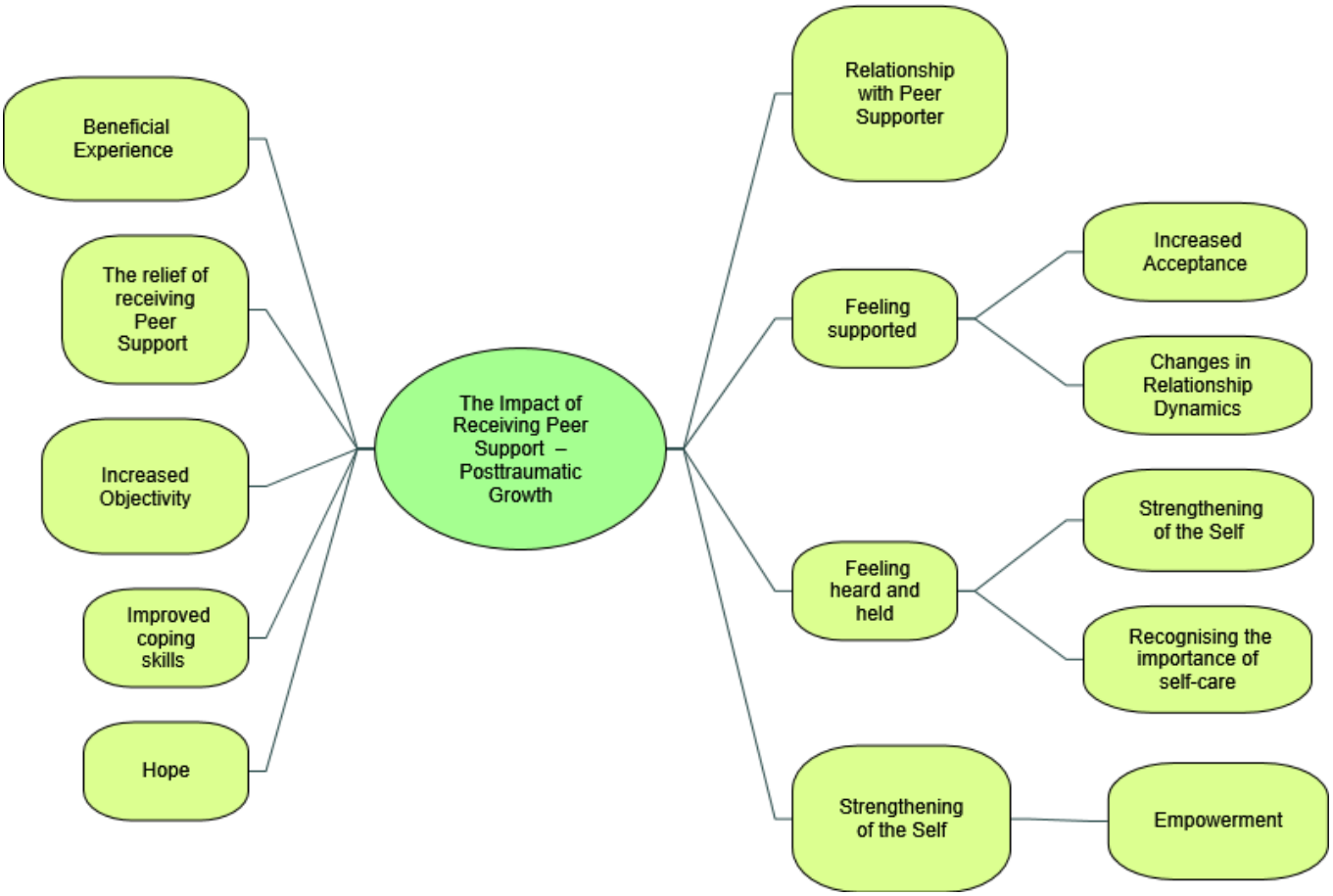
Superordinate Theme 1





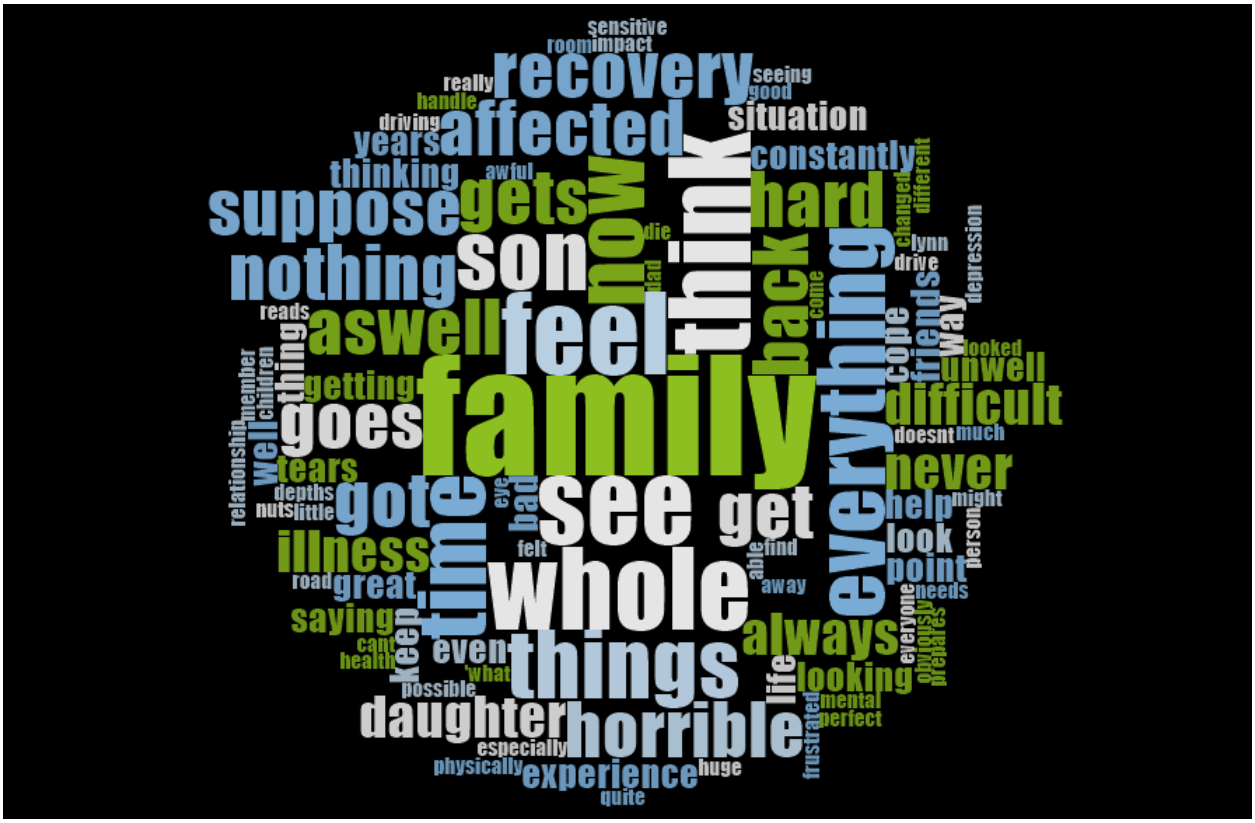

Selfish Nature of the illness
burnout
Feeling like a victim
Inner conflict
invisible suffering
resentment
Separating the illness from the individual
Stigma, shame & Fear
walking on eggshells
isolation
Silence around mental illness
trying to 'fix It'
perceived stigma

Superordinate Theme 2



Appendix L
NVivo word cloud on FFRPS

NVivo diagram of the most frequently used words during interviews in having a family member with SMI.



NVivo diagram of the most frequently used words during interviews in relation to FFRPS.

Appendix M
Superordinate & Subordinate Themes

The trauma of having a family member experience mental illness
➢ Fear ➢ Feeling alone ➢ Relentless worry ➢ Chaos and unpredictability ➢ Loss ➢ The emotional toll ➢ Vicarious trauma ➢ eroding of the self ➢ Fears and worries for the future ➢ Control ➢ trying to fix it ➢ Enmeshment ➢ Physical ill-health ➢ Frustration ➢ Feeling imprisoned ➢ Resentment ➢ Abusive aspect of the relationship ➢ Feeling powerless ➢ Suffering ➢ Inner conflict ➢ Alienating others ➢ punishing or self-protection ➢ Feeling like a victim ➢ Feeling Desperate ➢ Feeling helpless ➢ Feeling hopeless ➢ Feeling low ➢ feeling responsible ➢ Burden ➢ Views on the causes of mental illness ➢ being misunderstood - judged ➢ coming to acceptance ➢ surviving & improved coping **<u>The impact on the family</u>** ➢ The all-consuming nature of living with it ➢ lack of communication **<u>Stigma</u>** ➢ Silence around mental illness ➢ Shame ➢ Fear

Impact of receiving Peer Support – Post traumatic growth

- Feeling supported
- The relief of receiving Peer Support
- Being recognised as someone who needs support
- Being validated as a 'human being with rights'
- realising you are not alone
- connecting with the Peer Supporter
- Feeling heard
- Receiving empathy
- Feeling 'held' by receiving Peer Support -
- Recognising & asserting your rights
- Improved coping skills
- Hope
- determination
- Empowerment
- Post-traumatic growth –
- Strengthening of the self-
- offering to become a peer supporter
- Changing patterns of interaction
- Increased awareness
- increased understanding
- increased acceptance
- family recovery
- Greater clarity about one's role
- Feeling less responsible for it
- Greater sense of perspective
- Healthy boundaries
- No longer colluding with, or perpetuating unhealthy dynamics
- recognising the importance of self-care
- increased trust - letting go- positive changes
- Improved communication
- Separating the illness from the individual
- challenges of receiving PS
- suggestions for change
- Recommendations
- difference from other supports
- The booklet

Appendix N
Codebook Extract

17/12/2017 09:17

Coding Summary By Node
FRIENDS peer support pilot research

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Node

Nodes\\Phase 1 - Initial noting & coding\\Benefits of receiving Peer Support

Document

Internals\\interview transcripts\\transcript Alison

No		0.0306	2			
				1	DR	13/12/2017 20:05

i do t hink that that kind of support that anybody who is the main carer for the person who is ill needs it, there was nothing there for us to help us understand it

2	DR	13/12/2017 20:10

i'd receommend it [PS] even for a better understanding of what's going on, i've no education or anything.

Internals\\interview transcripts\\transcript Julia

No		0.0115	2			
				1	DR	12/12/2017 12:36

the friends support if was very relaxed, very informal, it's very gentle and it allows me to talk about what's important to me or to talk as much or as little about what's important to me and it doesn't put any pressures on me like there has to be a goal.

2	DR	12/12/2017 14:05

the friends is a very nice, gentle, non threatening support that over time i have i think i've relaxed more and i've been able to get more out of it.

Internals\\interview transcripts\\transcript Leah

				1	DR	11/12/2017 14:48

she's a great inspiration and just great advice and also the feeling that you are not on your own. Other people are going through this thing that you are going through, sometimes ten times worse, sometimes not, but everybody has the same, the reactions that we have …… and that we're healthy and that it's to be expected

				2	DR	11/12/2017 16:43

I'm full of all this positivity so that showed me how good they [Peer Support sessions] were, how important they are because even with that in the space of those few hours I was out of the house my attitude changed completely.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On
				3	DR	11/12/2017 16:44

And even though I've had the six sessions and they've finished, I've still got it, I keep it. Sometimes I'll go up into the room on my own and I'll just pull it all back up whatever I dealt with when I was at those meetings and I'll go downstairs with a

Internals\\interview transcripts\\transcript Martha

No		0.0174	1			
				1	DR	11/12/2017 21:15

it gives you great back up and help and there's nothing better i suppose, rather than whatever you read out of a book is not the same.

well my experience was very good because i had the one to one with [name of PS] but it came too little too late for me because my son got sick 27 years ago going on 28 so there was no help there for us, nobody to talk to

				2	DR	13/12/2017 21:10

just to have somebody to talk to with the same experiences, that was good and i hope X got something out of me, that we bounce off one another, that's what we need. the person with the mental illness live their own little lives, its the people that are around them that need to learn something and need the help. cos the people with the menatl illness are looked after, its how to manage them, howto not get aggressive with them, how to not eh get annoyed with them, to walk away from them, leave them to their own little devices, their quite capable of looking after themselves and that's whats needed.

Internals\\interview transcripts\\transcript Natalie

No		0.0037	1			
				1	DR	16/12/2017 21:51

i just feel as though the ps was excellent, i really found it very helpful.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Phase 1 - Initial noting & coding\\Benefits of receiving Peer Support\being recognised as someone who needs support/ feeling heard

Document

Internals\\interview transcripts\\transcript Alice

No		0.0709	5			
				1	DR	12/12/2017 17:25

i had to fill in forms at the start and i had to answer all these questions and when i was filling it in and when i was filling it in i said, you know what, i got a bit of therapy just from filling out the form. Would you believe that because nobody had ever asked me the questions that were on the form, nobody had ever asked me how i felt.

2	DR	12/12/2017 17:29

so even just filling out that form for me was a start, because you go around and you all you see, in doctors surguries for eample, is 'are you suffering from this?, are you suffering from that?' but there is nothing about 'are you living with someone who has a

3	DR	12/12/2017 17:29

you see i'd never thought of myself, i was so taken up with my daughter, with what she was going through, it was only.. i got a bit of relief to be quite honest because i was letting someone know how i felt.

4	DR	12/12/2017 17:30

there was somebody asking me how i felt, which had never happened before and she has suffered from depression since she was 14, so that's 5 years ago.

5	DR	12/12/2017 20:46

even my doctor, my own doctor, they know thatLynn has been diagnosied with depression but they never ask me how i felt and i never dreamt of asking them, you know, is there anything there for me because i didn't think there was.

Internals\\interview transcripts\\transcript Natalie

No		0.0170	1			
				1	DR	15/12/2017 22:24

i found the one to one great because it wasnt about your family member it was actually about you and what it was,you have to go in and say right im struggling a bit here. you're voice is being heard, you're voicing an opinion, it deosnt matter if its right or wrong,..... all your wanting to know is is it the right way to do things by saying no.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Phase 1 - Initial noting & coding\\Benefits of receiving Peer Support\Being validated as a 'human being with rights'

Document

Internals\\interview transcripts\\transcript Alice

No		0.0127	1

1	DR	12/12/2017 17:28

you go around and you all you see, in doctors surguries for eample, is 'are you suffering from this?, are you suffering from that?' but there is nothing about 'are you living with someone who has a mental illnes?'

Internals\\interview transcripts\\transcript Leah

No		0.0008	1

1	DR	11/12/2017 14:39

this was dealing with me as a person, as a human being with rights and we do you know

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Phase 1 - Initial noting & coding\\Benefits of receiving Peer Support\Changing patterns of interaction

Internals\\interview transcripts\\transcript Alice

No		0.0829	5

1	DR	12/12/2017 18:03

i was doing too much for my daughter and i've learned how to step back, it was only baby steps because i couldn't just cut straight away. i was doing too much for her. i was looking after her medication, following her around to take her medication so gradually i stepped back from that so now she's taking her own medication, i mean i cant force it down her mouth, she has to want to do it herself but before she'd never ask me for her medication, it was me going to her all the time but that has changed, gradually.

2	DR	12/12/2017 20:42

i wouldn't have talked to her brothers about what Lynn is going through but now, everytime she has an episode i tell them, the whole family are i involved so, i don't hide things from them anymore and they go up to her room and talk to her and the whole lot and tell her, we are here for you, everything, that was never there before. you know it was just me and Lynn and her father, i'd never gotten the whole family involved before.

3	DR	12/12/2017 20:47

my son's feel that i've gotten stronger in myself, the way i speak to Lynn, before i'd put my head up and walk up the stairs, you know? i use to be afraid, fear, fear, fear all the time but i've learned that i have to let go a small bit.

4	DR	12/12/2017 20:49

i think the fact that Lynn saw that i was willing to do something aswell, to to help myself.

5	DR	12/12/2017 20:52

i was probably putting too much pressure on her to be quite honest, not knowing what to do, but i've learned to back off.

Internals\\interview transcripts\\transcript Alison

No		0.0091	1

1	DR	13/12/2017 20:05

over the last 7 weeks she was sick and i handled it differently for a change.

Internals\\interview transcripts\\transcript Caoimhe

No		0.0836	6

1	DR	14/12/2017 20:43

Yes we are both more independent, she has a better social life than I do!

2	DR	14/12/2017 20:49

then the communication really opened up

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On
				4	DR	14/12/2017 20:54

Your be afraid ti say anything about the illness incease it made her feel bad. But when I came to

The more we talked about it, the less scary it was for everyone, it took away the scary element.

5	DR	14/12/2017 21:09

Since we have opend up that communication our rship has gotten so much stronger

6	DR	14/12/2017 21:26

It's so simple but it's so huge just that respect for eachother and opened up to appreciating each other more

Internals\\interview transcripts\\transcript Claire

1	DR	14/12/2017 15:53

it gave me a focus on me which i never did in years but em i know she's very ill this time around but im still focusing on me, like i went away for a day to a spa last week and i came back late afternoon and i says sam, she wasmt feeling great, i said really sandra you have to get up and get out if you can at all and she said but you werent here today and i said but im here every other day and that was a big lightbulb for me to say that any day that i can, i will help myself.

Internals\\interview transcripts\\transcript Edie

				1	DR	11/12/2017 19:25

so what i discovered in the 6 sessions is that, you know... i needed to respond with more kindness to him in a way aswell, that instead of being silent`like ask him 'how are you feeling today?'

				2	DR	11/12/2017 19:25

you know, engage with him more start asking him the questions that were being asked of me, you know 'well, how are you today? and what are you doing for your self, around self-care? and you know, what could you do to improve things? to motivate

i suppose i became kinder to him out of it...and i'm not unkind but i had kind of gone silent

				4	DR	11/12/2017 19:37

the key to all of this is that a little kindness goes a long long way, for all of us, and it was the kindness of [name of PS] and the caring and the love she showed towards me, i was able to give it back.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

i suppose that the biggest challenge to me was the response and my reactions to patrick's behaviour of living with him you know and for me to change that and be kinder

Internals\\interview transcripts\\transcript Julia

No		0.0211	5			
				1	DR	12/12/2017 15:00

the other thing i've learned through the friends is i'm just looking at what the Peer Supporter has been doing all along, she is getting me to think about how much i'm carrying and encouraging me to give my husband a little bit more responsibility.

at the moment i've pushed a lot more onto my husband and he's actually rising to the challenge but i have to look after that aswell because if he goes over the edge again, it's very, it it kind of happens before you know it so definitely the friends initiaive

				4	DR	12/12/2017 15:34

the dynamic is better between us, we're not arging as much im not as frustrated.

				5	DR	12/12/2017 15:35

my husband and i, there's just a much more positive synergy between us, it's like getting to know your partner again.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Internals\\interview transcripts\\transcript Julia

No		0.0301	2			
				1	DR	12/12/2017 14:34

i'd never understood the recovery piece before, i never convieved that there was family recovery as well as patient recovery and going through this process with the friends initiative has allowed me to see that and i'm delighted to see that aswell to knid of acknowledge that for myself because over the years i've not acknowledged my own needs in all of this, i have been so busy supporting my husband, supporting the family, getting myself to and from work that i've really not looked after myself in terms of my own mental health and psychologiccal wellbeing so tthat's where i think the friends initialtive can be so powerful

---

2 DR 12/12/2017 14:55

recovery for me is about taking the time to get over the stress and the trauma of having experienced a very difficult and challenging situation, so it's about getting over the stresses and the trauma that happened along the way and figuring out how to do that is difficult, when children are young they dont' always understand, i talk to my son he's 11 (tears) it's really hard when he calls his dad mad, you know it's hard

---

Internals\\interview transcripts\\transcript Natalie

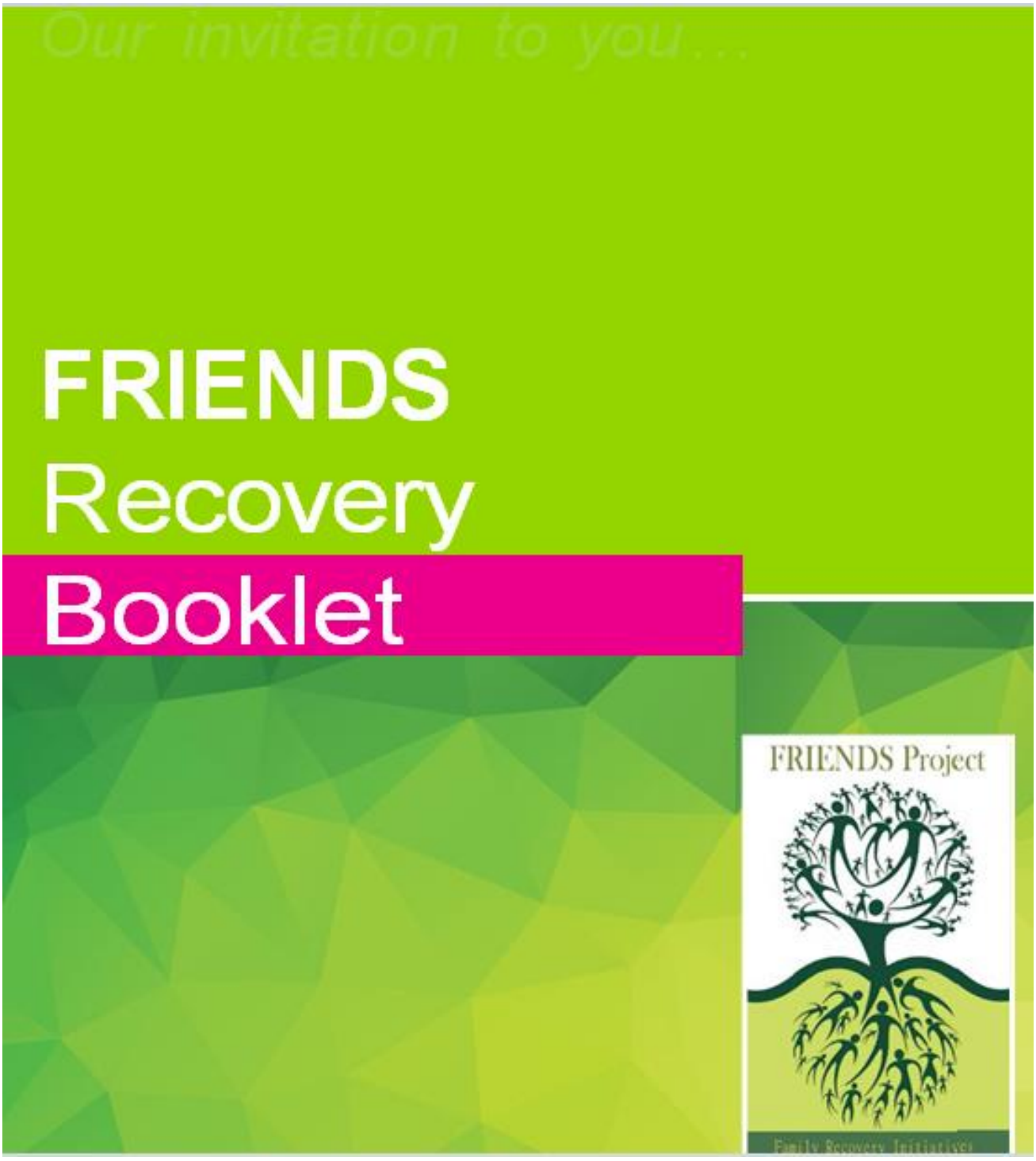
No		0.0369	3

1 DR 15/12/2017 15:49

we need to look for support and to talk, because we don't know what going on, we're in a family and we don't know what going on. What i've learned from this [the PS] is to communicate effectively as a family is the way forward, we were sadly lacking because we were all afraid to hurt each other. We were keeping things in and not speaking about things.

Appendix O
FRIENDS Booklet Extract

For a full copy of the booklet, please email a request to 12022659@studentmail.ul.ie



FRIENDS Steering Group
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Shine

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website: www.recover.ie

Headquarters Phone: 01 541 3715

Confidential email support:
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Áras Folláin

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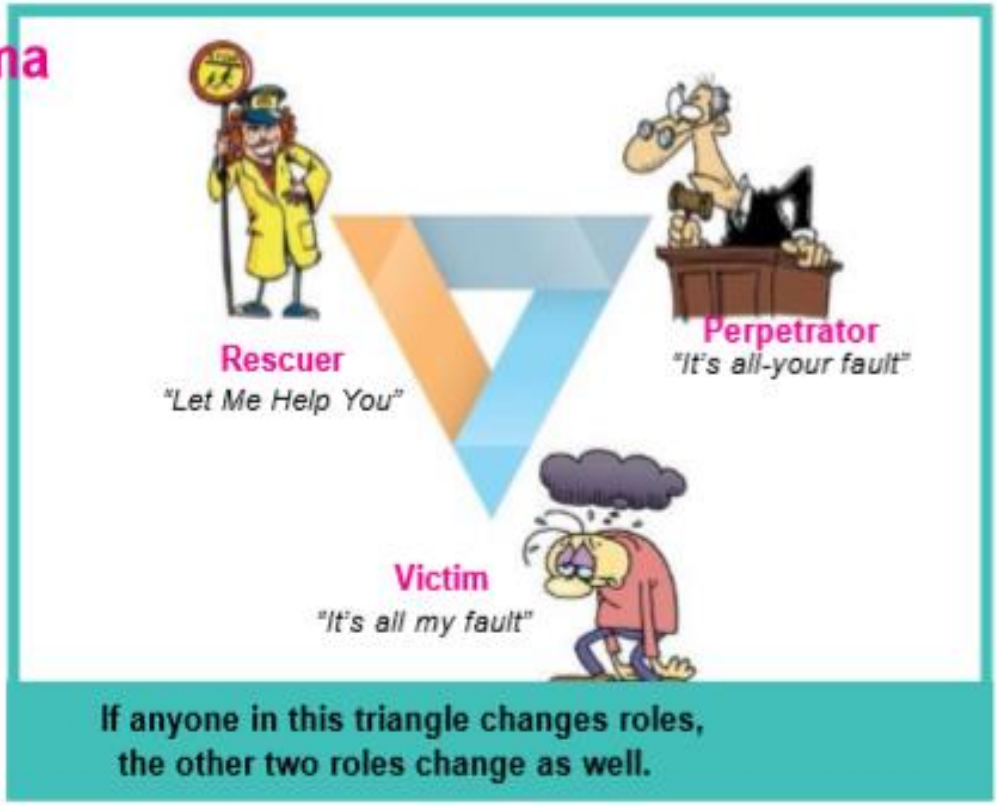
Phone:
06741906

The Drama Triangle



If anyone in this triangle changes roles, the other two roles change as well.

*RECOVERY AND THE DRAMA TRIANGLE

When we face a situation where distress and challenges come up it is easy for us to engage in a process called the drama triangle (Karpman, 1968). The drama triangle is a theory that was developed to explain a dynamic that occurs between people in unhelpful and unhealthy relationship dynamics. The drama triangle is a situation in which a level of discomfort arises within us in response to a situation and we react in one of three ways which we will describe below.

When we experience discomfort especially fear of the unknown, we try to manage by acting out one of the following roles (Persecutor, Rescuer and Victim). This serves as a short-term relief from the discomfort. But these roles act as a training ground for powerlessness. They prevent equality in relationships and have a long-term impact on relationships if we continue them. The sense of powerlessness will go on if we continue to take on one of these roles or assume a role for another.

FRIENDS